

REPORT

PATIENTS IN CONTROL

WHY PEOPLE WITH
LONG-TERM CONDITIONS
MUST BE EMPOWERED

Catherine McDonald

September 2014
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IDEAS to
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ACKNOWLEDGMENTS

The author would like to thank Sarah Bickerstaffe, who initiated this research and designed the survey. She is also grateful to HealthUnlocked, who facilitated the survey, and to everyone who responded to the survey.

The author would also like to thank IPPR's 'Health – Fit for the Future' project advisory board, whose members gave direction to the scope of this report and provided useful insights and guidance (and who are thanked individually in Appendix C).

She would also like to thank the Alzheimer's Society, Pfizer UK, Merck Sharp & Dohme Limited and Cerner Limited for their generous support for the project.

EXECUTIVE SUMMARY

Fifteen million people in England have one or more long-term health conditions, and the number of people with multiple conditions is rising (DoH 2012a). These are conditions which cannot be cured in most cases, but which can have a major impact on people's everyday lives. People with long-term conditions typically have contact with healthcare professionals for a relatively tiny amount of time – around three hours per year (Health Foundation 2013). This means that patients and their carers are, by default, taking the lead in managing their care for 99.95 per cent of the time. If people are not given more control, and supported to become experts at self-managing their conditions, they risk feeling abandoned and – if they are unable to self-manage – may be at an increased risk of health crises, which can require emergency health services.

People with long-term conditions use health services more often than other people, and need healthcare support not to cure or fix ailments, but to help them manage their conditions over a lifetime, as well to deal with 'flare-ups' and so on. We must do more to acknowledge patients' expertise on the effects of their condition(s) on their lives, and to marry it with expert medical advice, so that patients have more of a say over the services they receive.

The idea of giving more power to patients – in terms of self-managing their conditions and having more of a say over their services – is not a new idea in health policy. However, in this report we gauge, at scale, what people with long-term conditions actually think, and what kind of control and support they want. We present the results of a new survey of over 2,500 people with long-term conditions,¹ which asked them about their attitudes towards and experience of the management of their conditions.

We found that:

- Almost two-thirds of respondents² (63 per cent) were satisfied with the day-to-day management of their conditions. Of the just over a third (37 per cent) of respondents who were not satisfied, a relatively high proportion had not been given information and support when they were diagnosed.³
- Over three-quarters of respondents (77 per cent)⁴ told us that more of their healthcare could and should be managed independently at home – but they said that a lack of support and information was holding them back from doing so.⁵ This is a missed opportunity for both patients and the health service.
- People want a named contact for day-to-day queries. We asked which options, from a list of potential support and information, people would find most useful in the day-to-day management of their condition. A named contact for queries about any aspect of their care was by far the most popular response: three-quarters (75 per cent)⁶ said they would find this useful, and 57 per cent⁷ thought that having a named contact for telephone support and advice would reduce the number of times they saw their GP, went to hospital or used accident and emergency (A&E) services. The majority of respondents (70 per cent) also

1 Users in England of HealthUnlocked, 'the social network for health'. See <https://healthunlocked.com/>

2 See figure 3.3

3 See figure 3.5

4 See figure 3.1

5 76 per cent agreed with the statement, 'If you were better supported, more of your day-to-day health could be managed independently at home' – see figure 3.2.

6 See figure 4.1

7 See figure 4.3

wanted better access to their medical records. Significant numbers said that peer support and coaching would be useful (61 and 58 per cent respectively).⁸ Around half of these respondents thought that peer support (33 per cent) and coaching (29 per cent) would be likely to reduce their use of clinical services.⁹ Most people (56 per cent) thought that a healthcare plan would be useful,¹⁰ and people who were offered healthcare plans were much more likely to report satisfaction with the management of their condition (91 per cent, compared to 63 per cent of all respondents).¹¹

- Only around a third of respondents (35 per cent)¹² thought that personal health budgets would be useful. This may be in part because personal health budgets are not right for everyone, but some people commented that they simply hadn't heard of them or did not know what they were.
- In terms of assistive technologies, only a fifth (20 per cent) of people used devices to monitor their health and maintain their independence at least sometimes, and fewer (14 per cent) used apps.¹³ Less than a third (31 per cent)¹⁴ of respondents thought devices might be useful in future, and 24 per cent thought the same of condition-specific apps. Again, this may reflect the fact that they are not right for everyone or for every condition, but it may also be because people are unaware of the available and how they could benefit from them.

In this report, using the findings from our survey, we argue that more should be done both to recognise the large amount of self-management done by people with long-term conditions and their carers, and to better support and equip them to do so, so that people stay healthier for longer. We also believe that more should be done to enable people with long-term conditions and their carers to work in partnership with healthcare providers to agree upon the services that best fit their needs, rather than their being passive recipients.

Our report explores two aims:

- people with long-term conditions should have greater control over the services they receive
- people with long-term conditions should have greater empowerment and expertise in their day-to-day self-management of their conditions.

It describes what patients have told us they need in order to achieve these aims.

We consider these aims in the context of:

- the need to maintain the high quality of service that the NHS provides, in the face of rising pressure on NHS services due to long-term conditions and financial constraints
- the benefits to both people's health and service quality of giving people more control

There is broad consensus on the principle that the system should empower people.

- The NHS Constitution says that patients 'have the right to full information about treatment options, and to participate in decisions'.

8 See figure 4.1; 'useful' is here defined as a score of eight or more on the 10-point scale shown in figure 4.1.

9 See figure 4.3. This expectation would need to be tested.

10 See figure 4.1

11 See figure 4.9

12 See figure 4.1

13 See figure 4.12

14 See figure 4.13

- An objective of the NHS Mandate is ‘to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment.’¹⁵

However, the current system is not designed and delivered to prioritise patient empowerment first and foremost, and in some cases it hinders it. While there are good examples of people being empowered within the health system, there is little systematic evidence of patient empowerment being embedded – of it driving service design, and shaping strategies and service delivery across the board.

This report purposely focuses on what ‘good’ looks like from the point of view of people with long-term conditions who want to have more control. It explores what people’s priorities are, in order to truly put patients’ views at the centre of its proposals. It considers what giving patients more control means and requires, rather than jumping straight into service-redesign.

A subsequent IPPR report will ask the question, What would the healthcare system look like if empowering patients were the key driver for system design – and what would need to change in order to deliver it? It will consider what the implications would be for example, for the healthcare workforce, health education and information, technology, decision-making and commissioning, funding mechanisms and incentives, national policies, and the wider system.

Our recommendations in this report are ‘stepping-stones’ along the way: elements that should be put in place within the current system in the short-term to give people more control over their health and healthcare.

A named contact

1. People with long-term conditions should be offered a single, named point of contact for day-to-day queries about their health, healthcare and care coordination if they want one, and should be able to contact them easily and directly.

Ownership of medical records, and better information and advice

2. Patients should legally own their medical records, which should continue to be housed in the NHS, and they should be guaranteed free access to their medical records on demand. In the interim, a ‘patient’s healthcare log’, which is held by patients and which details their medical and clinical histories, should be considered.
3. It should be guaranteed that everyone diagnosed with a long-term condition – at the point of diagnosis and regularly thereafter – is offered information, advice and coaching about how best to self-manage their condition. The National Institute for Health and Care Excellence (NICE) should develop patient-friendly equivalents of each clinical guidance note relating to long-term conditions, including condition-specific checklists for patients to use to ensure that they are getting the services they need.

Peer support

4. Everyone diagnosed with a long-term condition should be able to access peer-to-peer support. Organisations operating in each local health economy – including voluntary sector organisations – should work together to enable the provision of peer-to-peer support mechanisms in communities, as well as enabling access to online peer-to-peer support.

15 <http://www.england.nhs.uk/ourwork/pe/sdm/commitment/>

Healthcare plans

5. Everyone with a diagnosed long-term condition should be guaranteed a healthcare plan covering their physical health, mental health and social care needs, into which they have substantial input and which they develop in partnership – and jointly agree – with their healthcare professional or care coordinator. Healthcare plans should include peer-to-peer support and assistive technology as a matter of course

Personal health budgets

6. The offer of integrated personal health and social care budgets, based on people's agreed healthcare plans, should be rolled out further, prioritising people who already have personal budgets for social care, and those with high levels of health needs.

INTRODUCTION

Around 15 million people in England have long-term conditions, and many of them have more than one (DoH 2012a). The number of people with multiple conditions is rising, which is placing rising demands on NHS services.

It is right to empower people and to give them more control over their health and healthcare. Such an approach rightly treats adults as autonomous individuals and, as we describe in chapter 2, helps them stay healthier for longer and could reduce demand on healthcare services.

There has been a great deal of discussion about the need to empower patients and to deliver new models of care, such as the 'house of care'¹⁶ model which considers the role, expertise and resources of people with long-term conditions. Our report details the results of our survey of over 2,500 people with long-term conditions living in England, in order to inform recommendations for specific actions that will help people with long-term conditions have:

- greater control over the services they receive
- greater empowerment and expertise in their day-to-day self-management of their conditions.

The results of the survey, conducted by HealthUnlocked, are a rich source of information about the attitudes and activities of people with long-term conditions, and they are set out in detail in chapters 3 and 4. The results give a particularly useful insight into the views of people who, as users of a health discussion website, have already demonstrated that they are particularly engaged and interested in their health and healthcare.

¹⁶ See section 2.2

1. THE CASE FOR ACTION

In this chapter we explain why we cannot go on as we are – with demand on health services from people with long-term conditions increasing and finances tight – if we want to maintain high-quality NHS services for all.

1.1 There are rising numbers of people with multiple long-term conditions, and rising demand on healthcare services.

Fifteen million people have one or more long-term health condition (DoH 2012a), of whom nearly half – 45 per cent – have more than one such condition (Paddison 2013). The majority of people aged over 65 have two or more long-term conditions; the majority of over 75s have three or more; and overall, the number of people with multiple conditions is rising (DoH2012a).

The focus of the NHS is no longer on transactional dealings with patients – fixing this, curing that. The Department of Health (DoH) states that ‘around 70 per cent of the total healthcare spend in England is attributed to caring for people with long-term conditions’ and ‘people with long-term conditions account for 50 per cent of all GP appointments’ (DoH 2012a). Typically, these conditions cannot be cured but do need managing.

As well as genetic factors, long-term conditions can be attributed in part to our ageing society (the likelihood of several long-term conditions increases with age¹⁷); to behaviours around diet, smoking, exercise and alcohol; to wider determinants such as quality of housing, security of employment and income (which have disproportionately negative effects on disadvantaged groups); and to medical advances – fewer people dying of strokes, for example (see below), means that more people are surviving them, but with potentially life-changing chronic conditions.

The House of Commons health select committee has stated that

‘Without improvement in both the rate of prevention of long-term conditions and the management of those with such conditions, the Department [of Health] estimates that by 2016 the cost pressures on the NHS will reach an additional £4 billion per annum compared to the baseline of 2010.’

HoC-HSC 2014

Case study: stroke

Stroke is an example of how the country’s health needs are changing. Although stroke continues to be one of the predominant causes of premature mortality and years of life lost in the UK, mortality rates have decreased significantly over the past 20 years.

Fewer people are dying directly result of stroke, and more people are living for longer after having suffered one. Unfortunately these extra years of life often entail ongoing health needs. As the number of years of life lost to stroke decrease, years lived with a disability as a result of stroke increase.

17 ‘A survey covering 1.75 million people showed the majority of people over 65 have two or more LTCS [long-term conditions], the majority over 75 have three or more, and more people have two or more conditions than one’ (DoH 2012b, referring to the Scottish School of Primary Care’s multimorbidity research programme, 2011).

- **Years of life lost due to stroke:** down by 41 per cent between 1990 and 2010.
- **Years lived with a disability as a result of stroke:** up by 50 per cent over the same period (Murray et al 2013).

Case study: dementia

The rising number of people diagnosed with dementia is one consequence of an ageing society, and represents a challenge for the future of UK health: more people will develop dementia, and more people with dementia will live for longer. Newly published data shows that by mid-2015 there will be 850,000 people with dementia in the UK, and that if no action is taken this figure will pass the two million mark by 2051. Diagnosis rates are still poor, with less than half of people with dementia receiving a formal diagnosis, and therefore access to the crucial support, advice and information that they need at this potentially life-changing time (Prince et al 2014).

1.2 There is a continued squeeze on NHS finances

Rising numbers of people with long-term conditions would present a challenge even if the funding situation were comfortable. However, in current circumstances, instead of the continuation of the historical 4 per cent annual real-terms increase in funding (Roberts et al 2012), 'it would be unrealistic to expect anything more than flat funding (adjusted for inflation) in the coming years' (NHS England 2013). Analysis shows that rising demand and flat funding will leave the NHS with a shortfall of up to £30 billion by 2021/22 (ibid). Almost double the number of trusts reported deficits for the year to 31 March 2014 than for the previous year (Dorsett 2014), and the British Medical Association has recently stated that doctors and medical students are concerned that cuts are 'destabilising a number of GP practices and could lead to their closure' (BMA 2014). At the same time, funding for social care has been reduced by £3.53 billion, or 26 per cent, since the start of the present spending round (ADASS 2014) – potentially affecting local authorities' ability to provide the types of social care that prevent avoidable hospital admissions, or that help people to get discharged from hospital promptly.

1.3 We need to act in order to maintain high-quality services

The NHS was recently reported to be the best healthcare system, in terms of quality, access and efficiency, among those of 11 nations studied by the Commonwealth Fund (Davis et al 2014). Yet relative to those same countries we spend nearly the lowest proportion of our GDP (9.4 per cent) on health. This demonstrates that the NHS is effective, efficient and economic, which is something to be proud of, and to defend.

We must recognise that as demands on the NHS increase, the service must change and be strengthened to enable it to respond to the pressures outlined above, and to continue to provide a high-quality national health service, free for all at the point of need.

The reason the NHS needs to change is *not* because something is fundamentally wrong with it. The opposite is true: something is fundamentally very right with it, and this must be preserved.

If we do not act – if demand increases and funding is flat – then patients will lose out. There would be increased pressure on the workforce, which would impact on quality; services could be rationed; waiting lists could increase; and people who are least able to navigate the system or make their voice heard would lose out the most.

As IPPR has said elsewhere, we should be 'strengthening the institutions that embody our collective aspirations and obligations' (Lawton et al 2014). There

can surely be no greater example of an institution that embodies our collective aspirations and obligations than the NHS.

Addressing the NHS's challenges

There are a number of ways to address these challenges, for example:

- **More funding for the NHS.** Current predictions are that funding will be flat in the short-term (NHS England 2013), but this contrasts with the historical 4 per cent annual increases (Roberts et al 2012) which have, until now, made the NHS able to respond to growing demand – and will potentially lead to a £30 billion shortfall by 2021/22 (NHS England 2013). IPPR has called for an NHS tax or national insurance increase to be considered in order to increase funding for the health services (Pearce 2014), and the Commission on the Future of Health and Social Care in England (Barker 2014) recently made a very helpful contribution to the funding debate.
- **More systemic public policy to help improve health and wellbeing using all policy levers,** including employment, housing and so on. There are huge opportunities for this with the move of public health into local authorities,¹⁸ where every policy lever can be used to improve communities' health, and traditional public health activities can achieve even greater impact by using the excellent community links and mechanisms local authorities typically have.
- **Greater integration of services, including more joined-up front-line services,** in order to provide 'whole-person care', whereby services are arranged around the holistic needs of people, and which aids the prevention of ill-health and, where there is ill-health, provides early intervention and joined up treatment for better outcomes. A number of initiatives in this area are already underway, such as the Integrated Personal Commissioning programme and the Better Care Fund. IPPR has previously published a report on redesigning services to provide whole-person care (Bickerstaffe 2013a), and the Commission on the Future of Health and Social Care in England recently set out arguments for moving to 'a single, ring-fenced budget for health and social care, with a single commissioner' (Barker 2014).
- **Greater productivity in NHS service provision,** including more innovation in how and where services are delivered, and stripping out unnecessary processes and activities. The King's Fund, among others, has recently reported and made recommendations on this area (Appleby et al 2014).
- **Empowering and enabling people with long-term conditions – and their carers – to have more control over the services they receive and become expert self-managers of their conditions** – which we explore in this report.

'At a time when resources are tight, we're going to have to find new ways of tapping into three¹⁹ incredible sources of 'renewable energy': [first,] boosting the critical role that patients play in their own health and care.'

Simon Stevens, chief executive, NHS England, April 2014²⁰

1.4 Summary

Rising demand on the system from people with long-term conditions means that the system will need to change if it is to continue to provide high-quality services to everyone who needs them. The challenge is made more acute by tight finances. There are many ways to respond, but this report considers one of them: empowering patients to give them more control, and expecting and equipping them to become expert self-managers.

18 See Marmot (2010) for a detailed exploration of the wider determinants of health.

19 The other two 'sources of renewable energy' cited by Stevens were: 'supporting the amazing commitment of carers and volunteers and communities to sustain their health and social care services,'; and 'unleashing the passion and drive of the million plus front-line NHS staff who are devoting their professional lives to caring'.

20 <http://www.england.nhs.uk/2014/04/01/simon-stevens-speech/>

2. EMPOWERING PATIENTS: WHY IT HELPS IMPROVE PEOPLE'S HEALTH AND THE QUALITY OF SERVICES THEY RECEIVE

This section will describe why we should do more to empower people with long-term conditions: doing so treats adults as autonomous individuals, it recognises and makes use of the expertise that people have about the impacts their conditions have on their lives, and it can drive better quality of services and better health outcomes.

What do we mean by 'empowering people with long-term conditions'?

Empowering people with long-term conditions means giving patients more control over their health and healthcare – on a day-to-day basis, at home and at work, and when receiving healthcare services. It means equipping people with the skills and support to do more for themselves so they can:

- become expert at self-management
- feel in control, to the extent they choose to
- have strong input into decisions that affect them
- feel that their medical team understands their circumstances, needs and wants
- have support and advice when they need it
- have services that fit around their lives, and which help them to live the lives they want to lead.

An important part of feeling empowered and in control is not feeling lost in the system. As one person told us:

'To be in control you need to know what's going to happen when, and who is going to look after you when you need looking after.'

Person with multiple long-term health conditions

2.1 Autonomy and self-determination are fundamental rights – and patients want more control

People have a right to self-determination. Just as we rightly expect control over every other aspect of our lives, it is time that we shift our collective mindset to both expect and enable people to have greater control over their health and healthcare.

Public services should enhance rather than diminish people's ability to make choices and influence decisions that affect them. A model of 'state-knows-best' disempowers and disengages people: it engenders a feeling that services are 'done to' people, and prevents them from seeing themselves as active agents who can influence the system.

In social care, greater control for citizens has its roots in the disability rights movement. Campaigners wanted an end to services that stripped people of the autonomy and freedom to lead independent lives, and that forced people to fit their lives around service provision rather than the other way around. The same principles should apply in health.

We recognise that people's appetite for greater control may vary across different groups, and as people's conditions progress. But even where there is reduced appetite or capacity for greater personal control it is not the case that the system should

automatically be prescriptive. Instead, there are empowering alternatives, such as equipping people’s carers to have greater control, or giving people in the early stages of their conditions the opportunity to put arrangements in place for the later stages.

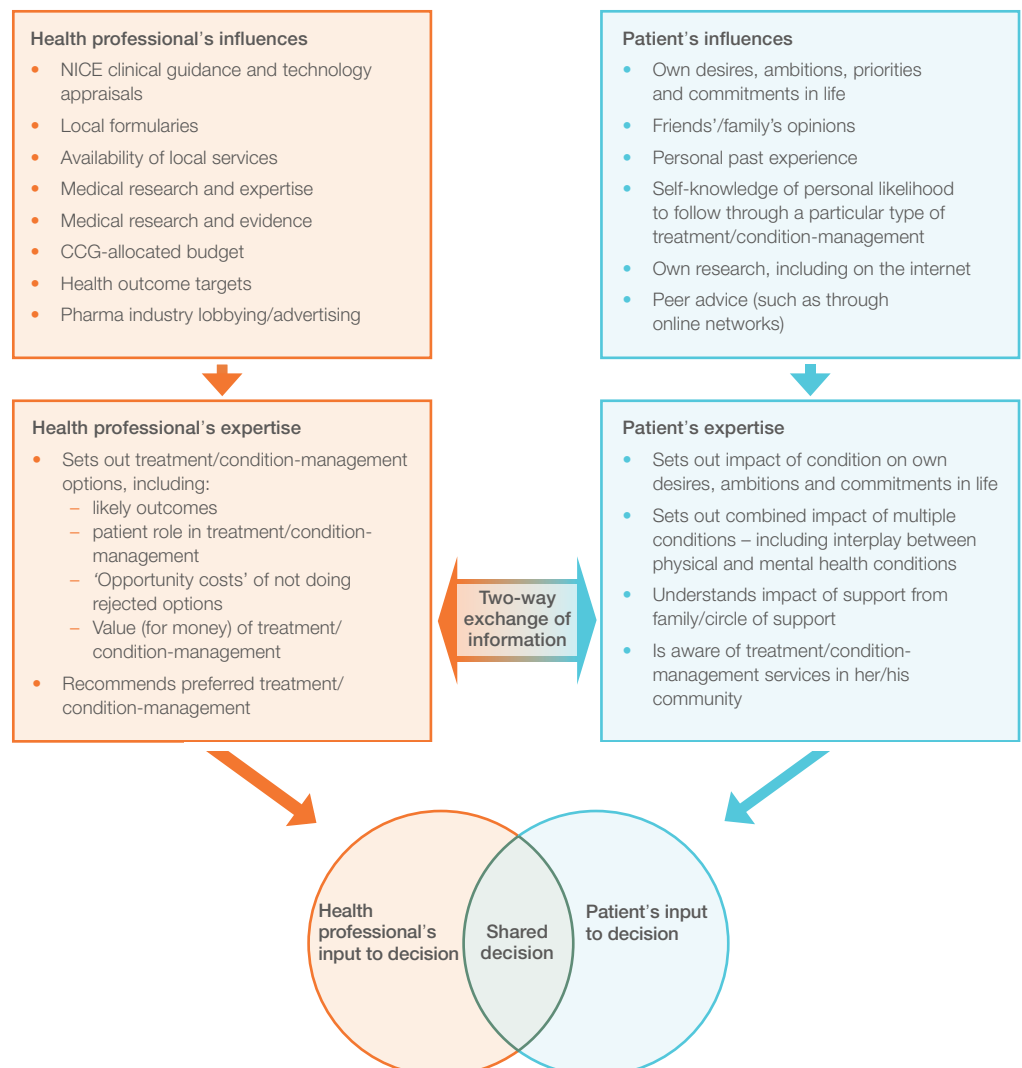
2.2 Patients are experts on the impact of their long-term conditions on their lives

The impact of long-term conditions on people’s lives varies considerably. People themselves are the experts in the effects that their condition(s) have on their wellbeing and the lives they want to lead. They best know the nature of their conditions, the interplay between multiple long-term conditions if they have more than one, the effect of the conditions on their mental wellbeing, the level of support they have at home and in the community, and the impact of wider factors such as quality of housing.

We need to move towards a model in which this expertise is recognised and used to inform decisions about overarching care management strategies and plans, as well as day-to-day condition management activities – one in which health professionals and patients have different roles to play, but both types of expertise are recognised.

Figure 2.1

A model of how the different influences, expertise and roles of health professionals and patients should inform shared decision-making



Without underplaying the medical expertise of front-line healthcare professionals, we should move away from the mindset (commonly held by patients and medical professionals) of ‘doctor knows best’, whereby patients passively have things done to them. Instead, all parties involved should recognise that both healthcare professionals and patients have expertise that is relevant to decision-making. The relationship between them should be one of partnership, in which both parties input into the exchange and both parties learn from it – in which both parties co-construct solutions. This approach uses and builds upon the ‘house of care’ model,²¹ which

‘...requires healthcare professionals to abandon traditional ways of thinking and behaving, where they see themselves as the primary decision-makers, and instead shifting to a partnership model in which patients play an active part in determining their own care and support needs.’

Coulter et al 2013

As Edgman-Levitan et al explain, a model which fully engages people in healthcare

‘...is not about achieving patient “compliance” with professional recommendations; it is about building skills and tools to promote dialogue and relationships between patients, families, healthcare professionals, and the community. We propose to change the clinical paradigm from “What is the matter?” to “What matters to you?”’

Edgman-Levitan et al 2013

Such an approach is

‘...in sharp contrast to the traditional approach to clinical decision-making – still prevalent in the NHS – in which clinicians are seen as the only competent decision-makers, with an expectation that they will make decisions for rather than with patients.’

Coulter and Collins 2011

Without the active support of health professionals engaging in shared decision-making, only the most determined patients will be able to forge an equal partnership. It is therefore essential that professionals play their part in shifting power to patients.²²

‘The health service can support a proactive public in promoting self-care... helping people to empower themselves... or supporting people to take a more active role in the diagnosis and treatment of a condition.’

Wanless 2002

2.3 Empowered patients mean better health and wellbeing

Giving people greater control over decisions affecting their health is not only a means to ends – in terms of better outcomes and better value – but an end in itself. Having greater control, in the sense of both feeling empowered and having the level of advice and support that one needs, is actually good for one’s health and wellbeing.

21 The house of care model ‘moves away from the “medical model” of illness towards a model of care which takes into account the expertise and resources of the people with long-term conditions (LTCs) and their communities to provide an holistic approach to their lives and help them achieve the best outcomes possible’. <http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/house-care-mod/>

22 IPPR will explore how the role of healthcare professionals will need to change in order to achieve this in a subsequent report.

'There is clear evidence that people wish to be in control of their own lives. There is also evidence that feeling in control is a factor in better physical and mental health. So it goes with the grain of both our individual and our collective interest to seek to maximise that control.'

Elvidge 2014

Research has shown that patient 'activation' (having the knowledge, skills, and confidence to manage one's own health) 'is strongly related to a broad range of health-related outcomes, which suggests improving activation has great potential' (Greene and Hibbard 2012).

Other research (Ryan and Deci 2000) has suggested that there are three aspects to enabling people to have wellbeing-enhancing empowerment and engagement:

- **autonomy** – the means people have to influence and control decisions that affect them
- **competence** – the support and information people need in order to be empowered, and what the system needs to do to recognise people's expertise and views
- **relatedness** – the relationships between front-line healthcare staff and patients, between patients and their support networks, and between peer groups of patients in similar circumstances.

These three themes are threaded through this report.

2.4 Empowered patients drive better outcomes through better self-management

People living with a chronic health condition typically see a health professional for only around 3 hours per year (around 0.05 per cent of their waking hours), and that contact time may not occur when people need support most (Health Foundation 2013). The rest of the time, people self-manage their condition, at home and in their communities.

We use the term 'self-management' to describe 'the individual's ability to manage the symptoms, treatment, physical and social consequences and lifestyle changes inherent in living with a chronic condition' (Barlow et al 2002).²³ This includes self-administering treatments such as insulin injections for diabetes and inhaler use for asthma, as well as lifestyle changes such as stopping smoking.

When people are supported to successfully self-manage their condition, a number of positive outcomes can be seen:

- improved patient knowledge and understanding of their condition
- improved confidence and coping ability
- improved health behaviours
- may improve adherence to treatment recommendations
- may improve health outcomes
- may reduce hospital admission rates
- may be cost-effective (National Voices 2014).

It makes sense to equip people with long-term conditions, and their carers, to be expert at self-managing their conditions at home for the 99.95 per cent of the time when they are without direct contact with medical professionals. Access to

²³ The term is often used interchangeably with 'self-care', but we use 'self-management' to make specific reference to those managing an ongoing health condition, as opposed to simply behaviours designed to promote good health or treat a minor ailment. We will occasionally use the term 'self-care' when citing authors who use it to refer to the management of ongoing conditions.

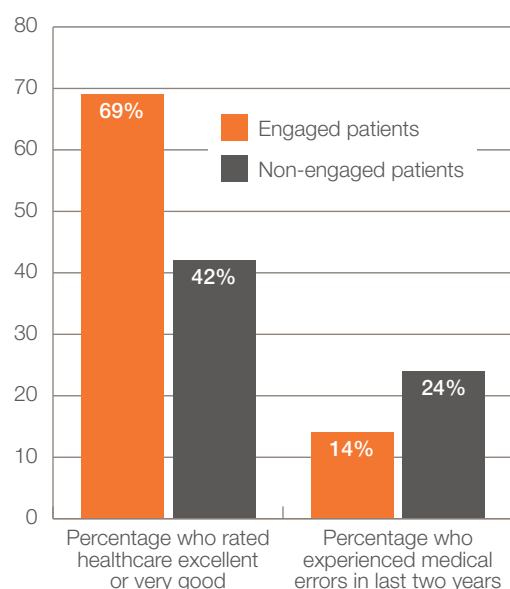
supported self-management needs to be available at the time of diagnosis or as near to that time as possible, in order to maximise the opportunities for people to gain knowledge and support. If people are not equipped and supported to self-manage, they are effectively left on their own, can feel abandoned, and can end up with complications and exacerbations, health crises, preventable trips to the GP or accident and emergency (A&E), avoidable suffering, and even premature death. Around 20 per cent of emergency admissions to hospital are thought to be potentially preventable, and many of these involve chronic conditions (Blunt 2013).

2.5 Empowered patients feel that they receive higher quality of care

Research has shown that patients who are engaged in their health and healthcare – through health literacy, shared clinical decision-making, self-care and self-management – are more likely to say that their healthcare is high quality, and less likely to report experience of medical errors (Edgman-Levitan et al 2013). Of course, this may be more correlation than cause – that is, it is possible that providers that engage well with their patients may be more likely to provide high-quality services in the first place.

Figure 2.2

Patients who are engaged in their healthcare report higher quality of care



Source: Edgman-Levitan et al 2013: 9

2.6 Empowered patients can drive improvements in service quality

Empowered patients have their views heard, through the choices they make and the feedback they give. Where people have a voice in shaping service provision, providers have an impetus to improve. There are many ways in which patients can currently have their voices heard²⁴ – including through participating in their local patient advice and liaison services²⁵ or a local Healthwatch,²⁶ by acting

24 It should be noted that there is a risk that people who best know how to navigate the system and get their voices heard – and who may not be representative of others in a similar circumstances – have the ‘loudest voices’. Decision-makers need to take this into account.

25 Hosted by local providers, these services respond to patients’ specific queries and concerns, and their overall findings should influence providers’ service improvement work.

26 Local Healthwatch groups were set up from April 2013. See <http://www.healthwatch.co.uk/>

as a foundation trust governor, through user feedback forums (including online forums²⁷ and other social media), through discussions with professionals, through complaints or petitions, or by raising issues with their elected representatives.

It is also argued that choice in service provision can drive up quality, as providers feel the consequences of failing to satisfy users and so are motivated to improve so that more people will choose to use their services. For this to happen, it is necessary for all potential users of a service to have: access to a range of high-quality options, and full information on those options, as well as a mechanism that allows them to actively make a choice. However, a problem with this model is that not everyone will have genuine choice, and not everyone is able to navigate the system to their advantage. This means that where demand for services is high, poor-quality providers still have patients to treat and do not suffer a consequence: individual purchasing decisions may not drive system-change. Furthermore, the people served by the poorly performing providers are typically those who are already more disadvantaged than others.

Research by Cooper et al (2011) showed that the policy of providing a choice of hospitals was effective in terms of driving improvements in quality. However, the choice people enacted was typically about a fairly straightforward transactional offer – for example, where to have one’s elective treatment. The policy offered little to people with chronic health conditions, for whom high-quality healthcare is characterised by support for self-management, coordinated care, and a focus on the home and community as the sites of care.

2.7 Public services that tackle complex issues should give more power and control to citizens

As IPPR has previously argued (Muir and Parker 2014), traditional models of public service delivery – typically top-down bureaucratic systems or market-based delivery models – may work for straightforward services, where a service is actively provided by or on behalf of the state and is passively received by the citizen – but they are less effective at addressing more complex issues. For complex issues, such as the management of long-term conditions, which have multiple, non-linear, ill-defined and often interconnected causes, and where people expect more personalisation and more of a say in the service they receive, a different model is needed: one which devolves power, connects services and deepens relationships. Muir and Parker call this model a ‘relational state’ model (ibid).

Central to this model is the idea that front-line professionals should develop a deep understanding of – a relationship with – the individual citizens they serve. That means treating people as individuals with their own personal wants and needs, and empowering citizens to be able to voice their views and shape the services they receive.

2.8 Summary

It is right to support people to have greater empowerment, especially where the issues are complex. Greater autonomy can lead directly to better health, and can be linked to better experiences of healthcare. Recognising that patients are experts in a range of areas that are relevant to their healthcare is a crucial factor in enabling empowerment. However, recognition alone is not enough – giving people greater control without giving them the support they need would be tantamount to abandoning them. In the next section we set out what people with long-term conditions told us about the empowerment and support they want.

27 Such as Patient Opinion: <https://www.patientopinion.org.uk>

Political leaders on empowerment in health services

'We should always [seek] to put more power in the hands of patients, parents and all the users of services. Unaccountable concentrations of power wherever we find them don't serve the public interest.'

Ed Miliband, leader of the Labour party, 2014²⁸

'We will empower patients as well as health professionals. We will disempower the hierarchy and the bureaucracy.'

Andrew Lansley, secretary of state for health (2010–2012), speaking in 2010²⁹

'We will be radical in challenging injustice, unaccountable institutions, and all vested interests whether in the private or public sector.'

Jon Cruddas MP, 2014³⁰

28 Hugo Young Lecture, 10 February 2014. <http://press.labour.org.uk/post/76238073973/ed-milibands-hugo-young-lecture>

29 <http://www.independent.co.uk/life-style/health-and-families/health-news/minister-defends-hospital-readmissions-penalties-plan-1994369.html>

30 Speech to the New Local Government Network annual conference, 12 February 2014. <http://press.labour.org.uk/post/76437199785/power-and-one-nation-jon-cruddas-speech-to-the-nlgn>

3. PEOPLE WITH LONG-TERM CONDITIONS WANT MORE CONTROL

BUT A LACK OF INFORMATION AND SUPPORT IS HOLDING THEM BACK

In this section we detail the results of our survey of over 2,500 people with long-term conditions who live in England.³¹ The people surveyed were users of HealthUnlocked, Europe's largest social network for health, where users provide and seek peer-to-peer support online. The methodology of this survey is described in appendix A of this report.

Overall, a significant proportion of people told us that they were not satisfied with the day-to-day management of their condition. Most respondents felt that:

- more of their healthcare can and should be managed independently at home
- more of their health could be managed independently at home if they were better supported, including through the following means (in order of preference):
 - a named contact for day-to-day health issues
 - better data and information
 - peer support
 - healthcare plans and personal health budgets
 - enabling technology.

Some people thought that these could also reduce their use of healthcare services

3.1 Most people with long-term conditions would like more of their healthcare to be managed independently at home – but a lack of information and support is holding them back

Over three-quarters of respondents (77 per cent) thought that more of their ongoing health problems could and should be managed independently at home – including more than seven in 10 people who use clinical services frequently. Only 3 per cent rejected the idea.

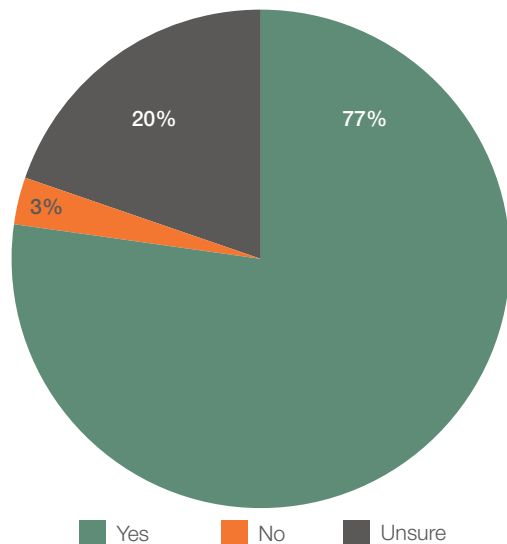
Three-quarters (75 per cent) of respondents agreed or somewhat agreed with the proposition that if they had better information and support they could become more expert at self-managing more of their care independently at home (see figure 3.2 below). People under 40 were more likely to agree with this statement than people over 40, and people on lower incomes more likely to strongly agree than others.

This suggests an untapped potential for patients to assume greater control and do more for themselves – and is a missed opportunity for both patients and the health service.

31 We surveyed only people with long-term conditions, not carers of people with long-term conditions.

Figure 3.1

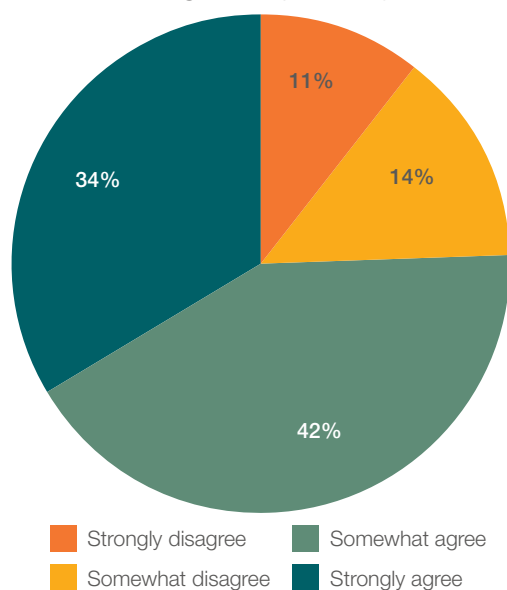
Responses to question 16, 'Do you support the idea of trying to manage more ongoing health problems at home?'³²



Source: This and all subsequent graphics illustrate the findings of polling conducted by HealthUnlocked in March 2014, commissioned by IPPR. See appendixes A and B respectively for the methodology and full text of this survey.

Figure 3.2

Responses to question 14, 'Do you agree with the statement, "If you were better supported, more of your day-to-day health could be managed independently at home?"'



32 The full text of the survey is reproduced in Annex B of this report.

3.2 A significant proportion of people are not currently satisfied with the day-to-day management of their healthcare

Most of the people we surveyed (63 per cent) said that they were satisfied with the day-to-day management of their condition(s), but over a third (37 per cent) were not (see figure 3.3 below).³³ People with higher incomes were more likely, and older adults were far more likely, to be very satisfied than others.

Some respondents embraced their self-management role.

'I am capable and willing to manage my own health at this stage of my life.'
HealthUnlocked survey respondent

'Through the excellent support that I already receive I am able to manage my health independently at home.'
HealthUnlocked survey respondent

Some had adapted to their situations.

'I have learnt to manage it myself.'
HealthUnlocked survey respondent

'I have been given more than sufficient information to be able to self-manage my condition.'
HealthUnlocked survey respondent

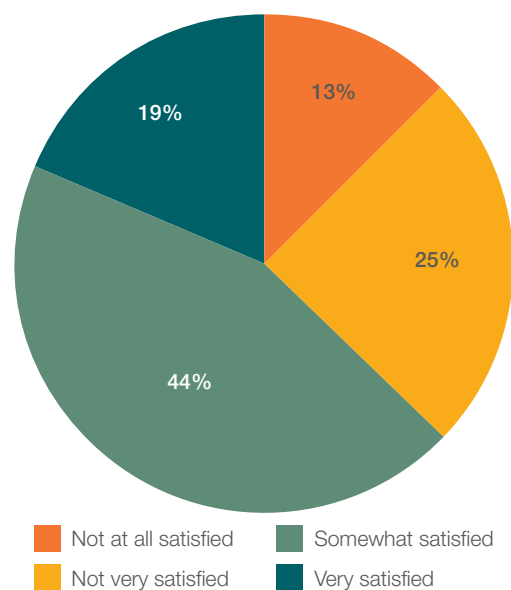
Others simply felt abandoned.

'[I have] been largely left to cope alone.'
HealthUnlocked survey respondent

'After being diagnosed I was just left to get on with managing things on my own.'
HealthUnlocked survey respondent

Figure 3.3

Responses to question 4, 'In general how satisfied are you with the day-to-day management of your (main) health condition?'



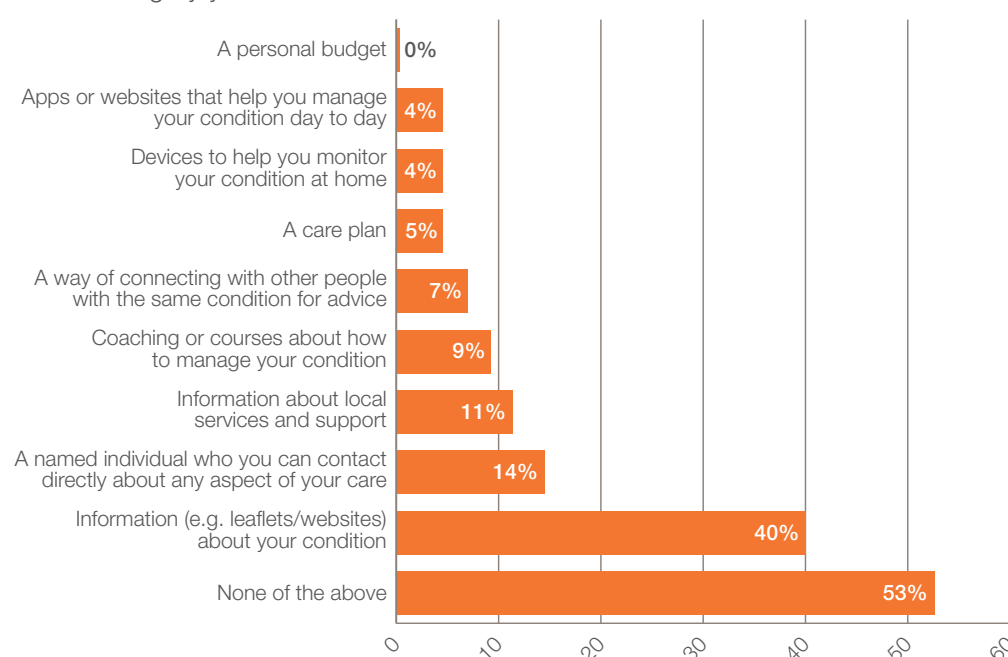
33 See figure 3.3

3.3 Over half of respondents were not given information and advice at the time of their diagnosis – and people who were not offered information and support when diagnosed were most likely to be dissatisfied with the management of their condition

Just over half (53 per cent) of respondents said they were not offered any support or information when they were diagnosed (see figure 3.4). Survey responses showed that people who were offered the least information and support at the time of their diagnosis were least likely to be satisfied with the day-to-day management of their health condition (see figure 3.5).

Figure 3.4

Responses to question 6, ‘When you were first diagnosed were you offered any of the following by your medical team?’



These responses suggest that two factors are critical to people’s ability to expertly self-manage their conditions:

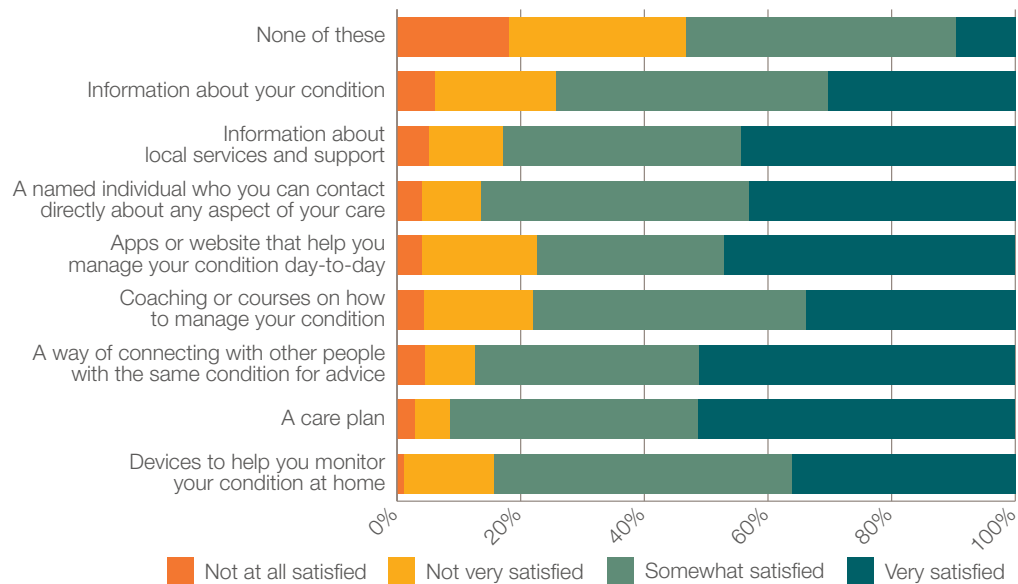
- people having the expectation that they will be responsible for self-managing their condition(s) almost all the time
- people having all the information and support they need to expertly self-manage their condition(s).

3.4 Summary

Among the people we surveyed there was a strong demand for more of a say over the way their conditions are managed overall and on a day-to-day basis, but they often lacked the support they needed to do so. We therefore now need to consider what types of support people say they need.

Figure 3.5

Respondents' satisfaction with the day-to-day management of their (main) health condition (question 4), subdivided according to their answers to question 6, 'When you were first diagnosed were you offered any of the below by your medical team? (select any that apply)'



4. HOW DO WE EMPOWER PATIENTS?

Empowering people is not about leaving them on their own to get on with things: the opposite is true. It is about ensuring that they are properly equipped and able to take more control. Based on research on the broad types of support that people might expect to receive, we asked our survey respondents how useful a range of services would be in helping them manage their day-to-day health. They ranked these services in the following order:³⁴

- named individuals who can be contacted directly about any aspect of their care: 75 per cent said this would be useful³⁵
- good data and information about their medical conditions – including access to medical records (70 per cent said this would be useful) and coaching on how to manage their condition (58 per cent)
- peer support from people with similar conditions: 61 per cent said this would be useful
- healthcare plans and personal healthcare budgets, where people want them: 56 per cent said a care plan would be useful, but only 35 per cent said that a personal health budget would be
- enabling technology: 31 per cent said devices or sensors would be useful, and 24 per cent said that condition-specific apps would be useful.

We will now explore each of these findings in greater depth.

4.1 A named contact for day-to-day queries about any aspect of people's care was considered to be potentially most useful

Previous IPPR research has found that people who use public services place a very high value on consistency of relationships with professionals, and their ability to form deep relationships with those professionals (Muir and Parker 2014).

Three-quarters of respondents (75 per cent) felt that having a named individual who they could contact about any aspect of their care would be useful or very useful in the day-to-day management of their health condition, but just 14 per cent of respondents said they were offered a named person to contact when they were diagnosed.³⁶

The question of who this named, contactable individual should be, and what experience or qualifications he or she should have, is also an important one.

34 That is, those services that the highest proportion of respondents gave a score of eight or more on a 10-point scale, from 'not useful' (1) to 'very useful' (10) – see figure 4.1.

35 'Useful' (and 'very useful') is here defined as a score of eight or more on the 10-point scale described above and in figure 4.1.

36 In response to question 6 – see figure 3.4.

Figure 4.1

Responses to question 9, 'On a scale of 1–10 how useful would the following services be for the day-to-day management of your health condition? (Where one is not useful and 10 is very useful)'

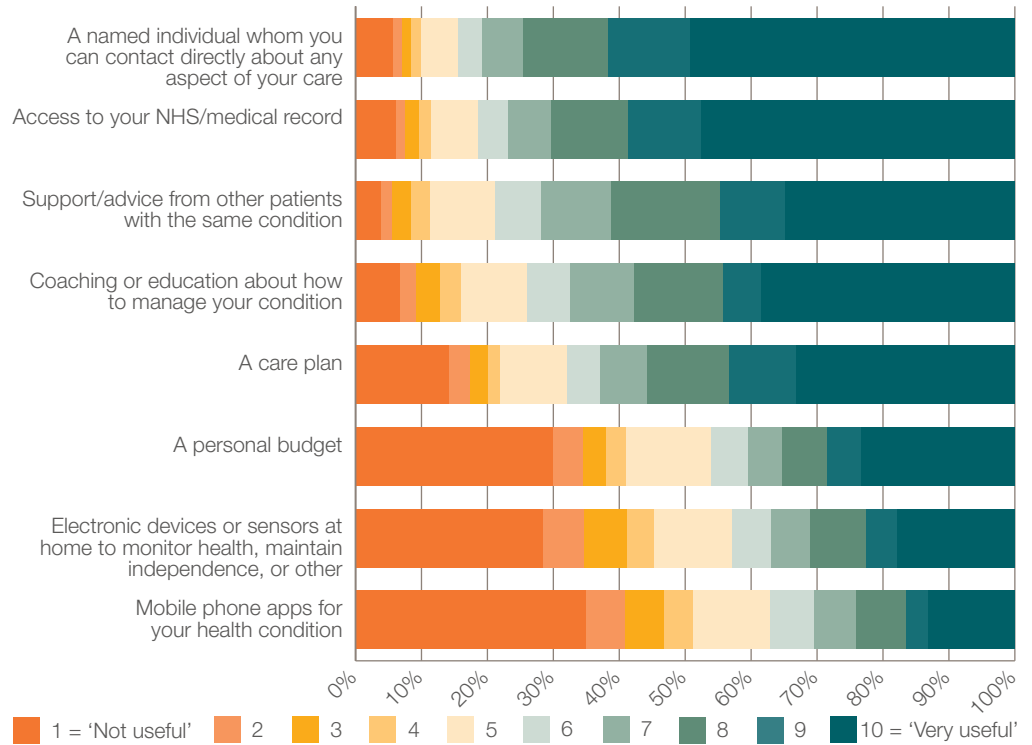
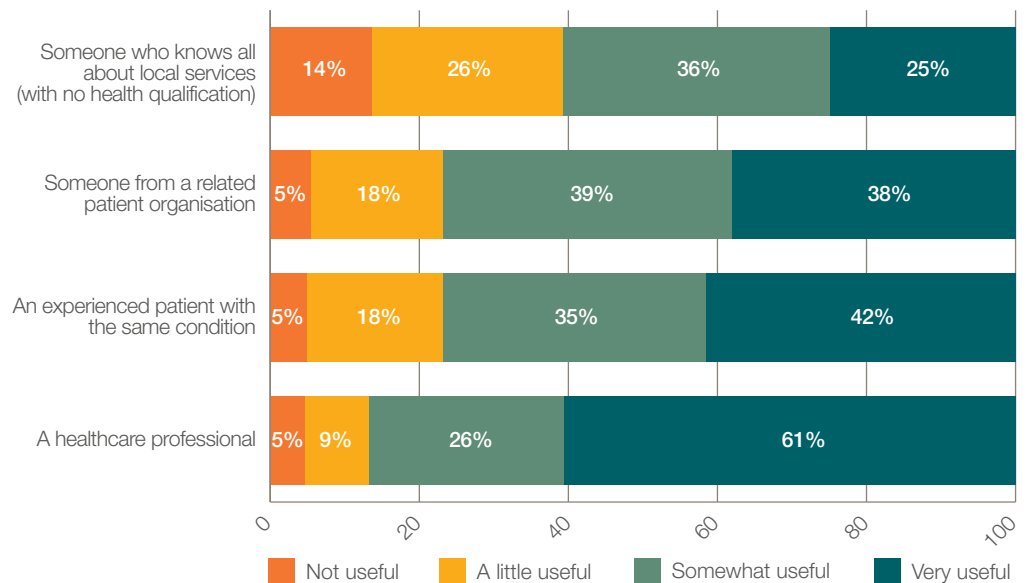


Figure 4.2

Responses to question 10, 'If you were given a named contact to telephone/email directly about day-to-day health issues, how useful do you think the following would be?'



Most respondents said that they would prefer the contact to be a healthcare professional, but many also thought the role could be effectively performed by someone with the same condition(s) (see section 4.3, on peer support), someone from a related patient organisation or a non-health expert on local services.

'My GP doesn't have any specialism in my condition, so probably won't be able to recognise early signs of deterioration in my condition.'

Person with a long-term condition

Dementia Advisers

There is increasing evidence demonstrating the benefits of such support for people with dementia and carers. Research shows that Dementia Advisers, who act as a named contact for people and provide them with post diagnosis support, help people affected by dementia to live better, and to plan for the future (Clarke et al 2013)

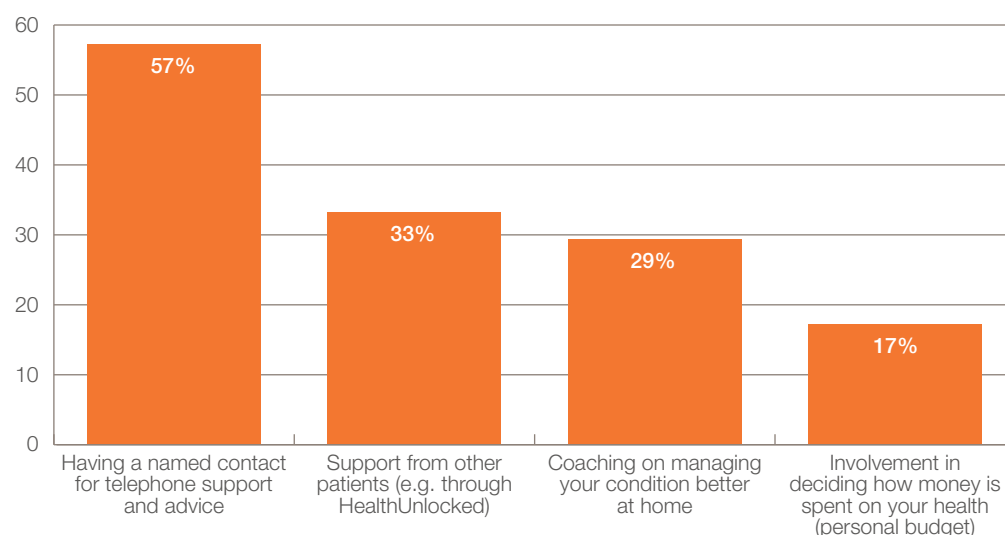
A majority (57 per cent)³⁷ of respondents thought³⁸ that having a named contact for day-to-day telephone support and advice would reduce the likelihood that they would need to use clinical services like hospitals, A&E departments and GPs (see figure 4.3 below).

'If access to a professional were available it may well reduce the number of A&E attendances and/or GP appointments.'

HealthUnlocked survey respondent

Figure 4.3

Responses to question 15, 'Would any of the following reduce the likelihood that you need to use clinical services (hospital, A&E, GP etc.)?'



A named contact for day-to-day support for everyone with a long-term condition differs from the government's policy of requiring that all people aged 75 or over have a named GP;³⁹ it also differs from proposals concerning named consultants and 'whole stay doctors' accountable for people's care throughout their stays in

³⁷ See figure 4.3

³⁸ We recognise that this would need to be tested in practice

³⁹ <http://bma.org.uk/working-for-change/negotiating-for-the-profession/bma-general-practitioners-committee/general-practice-contract/gp-contract-faqs/gp-contract-faqs-named-gp>

hospital.⁴⁰ Rather, the role would provide an ongoing point of contact to provide advice and information whenever someone requires.

The named contact might also have a care coordination role, overseeing the coordination and delivery of healthcare services, joining up disparate services, signposting services, and potentially holding service providers to account on behalf of patients. In this respect, there may be lessons to learn from the coordination of healthcare for children with long-term conditions, as well as from specific examples in adult healthcare.

Current services offer examples of different care coordinator roles. In the Torbay integrated care project, the care coordinators have no professional background (Thistlethwaite 2011); in Cornwall staff and volunteers from Age UK Cornwall provide the coordination function (Creaven 2013); and in virtual ward arrangements, it is usually the 'ward clerk' who can be contacted by phone and email, and passes information between key staff and patients (Lewis et al 2011).

Over a quarter (26 per cent) of respondents already communicate with their healthcare team electronically (for example, emailing the healthcare team or booking appointments online) at least sometimes, yet 59 per cent had never done so (see figure 4.5). This compares poorly to some health organisations in the US, which make much greater use of technology,⁴¹ and indicates that there is scope for greater use of it in the UK.

Recommendation: People with long-term conditions should be offered a single, named point of contact for day-to-day queries about their health, healthcare and care coordination if they want one, and should be able to contact them easily and directly.

4.2 Good data and information about their medical conditions, and about how to navigate the system, is key to empowering and supporting patients

NHS medical records

Currently, people's NHS medical records are held and owned by the state. If we are looking to empower patients, patients should be considered the owners of their medical records. That means that they should have real-time, on-demand access to their records, and that in the interim they should possibly have a 'patient's healthcare log' of their medical and clinical history.⁴² Patients should be able to share these as they see fit, in order to aid their day-to-day self-management and help them access the services they need. Seventy per cent of survey respondents felt that access to their NHS medical records would be useful or very useful in the day-to-day management of their health condition(s).

40 <http://www.bmj.com/content/348/bmj.g1104> (subscription required)

41 For example, Kaiser Permanente's HealthConnect programme allows patients to communicate by email with their medical team, as well as access their records and make appointments online (Ham and Curry 2010). Nine out of 10 patients with chronic conditions who used Kaiser's online system said it helped them to more effectively manage their conditions (Wright 2013).

42 This could be modelled on 'patient passports' for adults with learning disabilities, or on the 'My Healthcare Passport' created by the Royal College of General Practitioners (RCGP) Northern Ireland for patients with progressive, life-limiting illness. This latter tool was created to alleviate a number of problems, which the RCGP described as follows:

'...patients, families and carers can often feel overwhelmed with the amount of information and the number of healthcare professionals they come into contact with throughout the healthcare journey. Some patients have communication issues due to their condition and detailing their medical history can be difficult and frustrating. This tool was specifically developed to help alleviate these problems.'

Source: <http://www.rcgp.org.uk/rcgp-near-you/rcgp-northern-ireland/my-healthcare-passport.aspx>

Patients are currently able to access their records,⁴³ but it can be a very laborious process for patients and medical professionals alike:⁴⁴ it typically requires planning, a request, an appointment to view and in some cases a fee. In some cases people are already able to access their records when they want to, but this is not the norm. The King's Fund (2013) has called on Clinical Commissioning Groups and primary care teams to 'allow patients to access their electronic medical records'.

'Since more information became available to me my need to visit the GP has decreased. I can view my results/medical record online at my new surgery. This is fantastic and really helps me to manage my own health.'
HealthUnlocked survey respondent

Recommendation: Patients should legally own their medical records, which should continue to be housed in the NHS, and they should be guaranteed free access to their medical records on demand. In the interim, a 'patient's healthcare log', held by patients and detailing their medical and clinical histories, should be considered.

Healthcare information and coaching about conditions

The quantity and quality of information that people receive about their long-term condition varies. While the National Institute for Health and Care Excellence (NICE) provides clinical guidance on how to treat different conditions, much of it is not accessible to people without medical training. It would be helpful if patient-friendly versions of the same information was produced at the same time, and was offered to patients as well as made available on, for example, NHS Choices: this would mean that patients know what to expect. In addition, voluntary sector organisations specialising in particular long-term conditions are a good source of easily accessible expert information. There are currently some good examples of user-friendly 'checklists' that tell patients what to expect when they have specific conditions;⁴⁵ these could be more widely used and incorporated into patient guidance.

Such straightforward messaging would also help patients to be more discerning about information they receive through other sources, such as the sometimes overly-simplistic health messaging they may see in the media or from other sources.⁴⁶ It would also help patients to critically evaluate – and, where necessary, challenge – the healthcare advice they receive.

As noted above, just over half of respondents (53 per cent) say they were not offered any information when their long-term condition was diagnosed (see figure 3.4). As we saw, this had a negative impact on their satisfaction with the management of their condition (see figure 3.5).

'I manage the majority of my care. But I sadly lack information when required. I receive copy letters from my consultant with no support to explain some of the contents.'
HealthUnlocked survey respondent

To equip people to self-manage, it is imperative for healthcare professionals to provide good information and coaching to people about their conditions at the point of diagnosis and periodically thereafter. People we surveyed said that they used a range of sources for information about their condition(s).

43 See <http://www.nhs.uk/chq/pages/1309.aspx?categoryid=68>

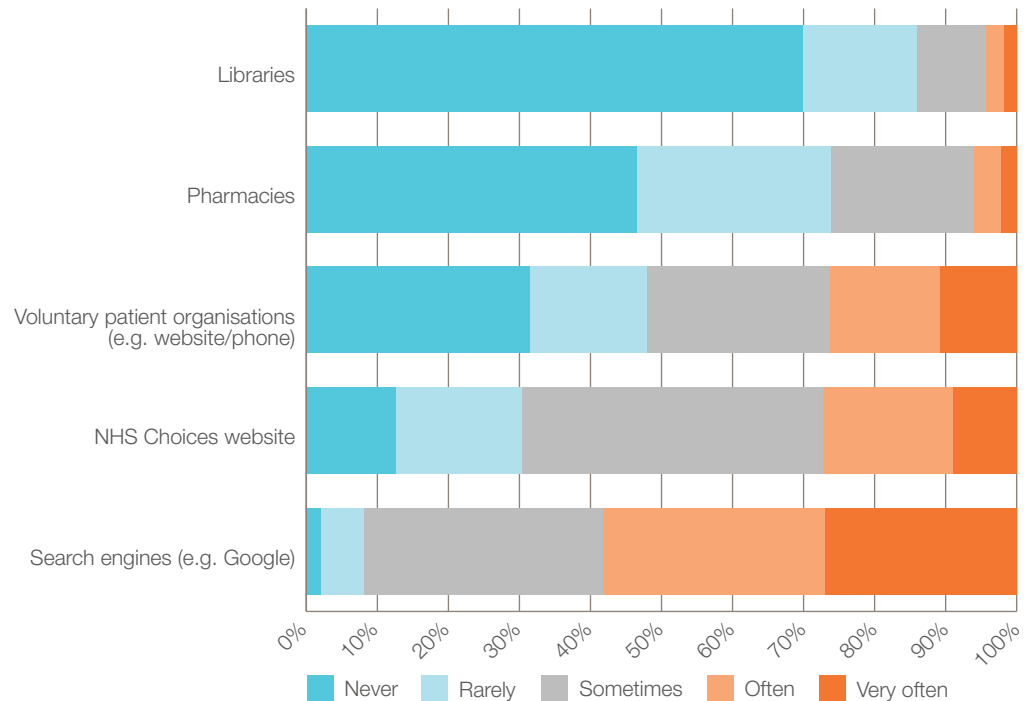
44 Unless a medical professional decides to informally show someone their own records. Note that the GP has decision-making power here, not the patient.

45 For one example, concerning chronic obstructive pulmonary disease, see <http://www.innovationunit.org/sites/default/files/COPD%20Care%20Checklist%20Report.pdf>

46 The NHS Choices website's 'Behind the headlines' feature provides 'an unbiased and evidence-based analysis of health stories that make the news'. <http://www.nhs.uk/News/Pages/NewsIndex.aspx>

Figure 4.4

Responses to question 7, 'In addition to HealthUnlocked, how often do you look for information about your health outside your medical team?'



It is important also to note that primary care professionals, other than GPs, are potentially being under-used as sources of front-line advice. For example, pharmacists are easily accessible in the community (and some people may be more comfortable speaking to a pharmacist than a GP), yet our survey showed that nearly half of respondents did not seek advice from pharmacists. It is therefore likely that pharmacists are being significantly under-used as community resources.⁴⁷

Recommendation: It should be guaranteed that everyone diagnosed with a long-term condition – at the point of diagnosis and regularly thereafter – is offered information, advice and coaching about how best to self-manage their condition. NICE should develop patient-friendly equivalents of each clinical guidance note relating to long-term conditions, including condition-specific checklists for patients to use to ensure that they are getting the services they need.

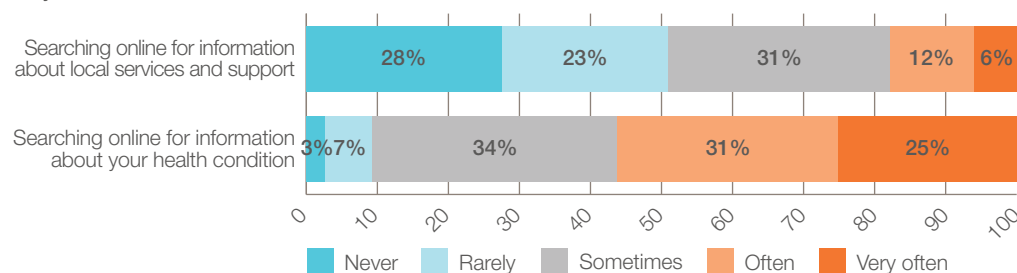
Almost all respondents (92 per cent) said that they get information on their conditions and associated healthcare services from internet searches at least sometimes – with NHS Choices being a well-used resource – and almost all (90 per cent) use the internet to search for services (see figure 4.5 below). This high level of internet use as a means of finding out about conditions is to be expected given the survey sample – people who use a health website – and leaves open the question of where people who are not online get any additional information about their conditions. We know that people who are older or who have work-limiting conditions are less likely to be online than others (McDonald 2014), which suggests that people with long-term conditions may be less likely to be online than others, and so less likely to be able to access health information

⁴⁷ Dentists are also often able to advise on factors relating to people's long-term conditions, and typically see people on a more regular basis, including at times when people are not experiencing any acute medical needs. However, we did not ask about this in our survey.

on the internet. In at least the short term, while programmes and policies to get more people online are still taking effect, services should provide information in forms that are accessible to people who are not online.

Figure 4.5

Responses to question 8, ‘How often do you use search online for information about your condition or health services to improve the day-to-day management of your health?’



4.3 Peer support from people with similar conditions helps empower and support patients

Our survey respondents said that peer-to-peer support would be one of the most useful ways of supporting self-management (see figure 4.1). In one sense this is unsurprising, given our survey sample,⁴⁸ but it at least demonstrates that where people access peer-to-peer support it is valued.

Sixty-one per cent of respondents said that support or advice from other patients with the same condition would be useful or very useful in the day-to-day management of their health condition, and 88 per cent of respondents who had been offered peer support when they were diagnosed said they were somewhat or very satisfied with the day-to-day management of their condition (see figure 4.6).

Increasing reliance on peer (as opposed to professional) advice is in-keeping with developments seen in many other industries, such as travel, and also supports what behavioural science tells us about our natural openness to receiving messages from people who we perceive to be ‘like us’. In the health context, this advice can be about which services to ask for or choose based on users’ feedback, but can also be on how to self-manage symptoms on a day-to-day basis.

‘The most helpful thing I have found is talking to other people with the same problem in our support group.’

HealthUnlocked survey respondent

Research has suggested that people find online networks helpful for understanding side effects and learning about symptoms. Wicks and Little (2013) found that among users of PatientsLikeMe,⁴⁹ substantial minorities felt that they received better care, improved their medication compliance, experienced reduced treatment side-effects and reduced their emergency room visits. Respondents to our survey much preferred using a specialist health network for online peer support to using generic social media. One advantage of online groups – which of course are only available to people with internet access – is that there is no waiting list and no closing times.

48 Of people using a health social networking website.

49 <http://www.patientslikeme.com/>

Figure 4.6

Breakdown of responses to the 'peer support' option in question 9, 'On a scale of 1–10 how useful would the following services be for the day-to-day management of your health condition? (where one is not useful and 10 is very useful)', (detail from figure 4.1)

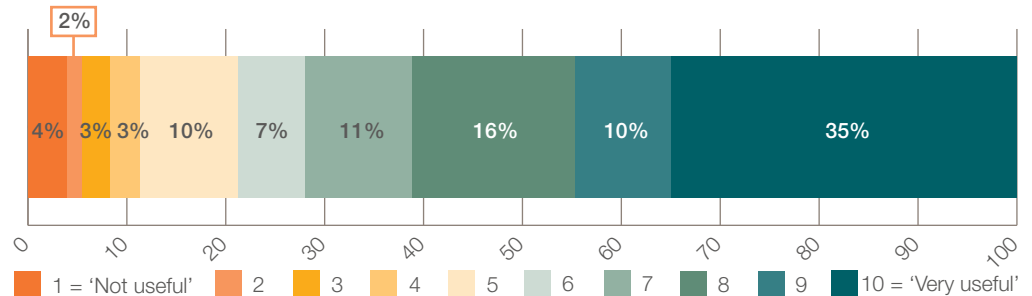
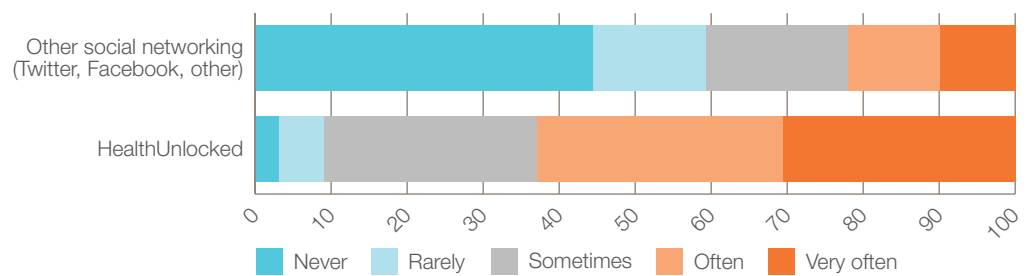


Figure 4.7

Responses to question 8, 'How often do you use social media to improve the day-to-day management of your health?', related to peer support



Face-to-face peer support based around local groups can help to build social ties that strengthen communities and decrease social isolation, which not only has a direct impact on people's health and wellbeing but enables people to share experiences and learn from each other. IPPR has previously recommended local 'neighbourhood networks' specifically targeted at older people (McNeil and Hunter 2014). These could be used to identify and bring together people who would benefit from sharing their experiences of managing long-term conditions. For example, the Alzheimer's Society runs dementia cafés where people with dementia and their partners and/or carers can regularly come and meet others with similar circumstances.

Dementia cafés

The Alzheimer's Society says:

'Dementia Cafés provide a safe, comfortable and supportive environment for people with dementia and their carers to socialise.'

'As well offering a range of fun and engaging activities, Dementia Cafés give both carers and people with dementia a chance to get information and advice and talk to others with similar problems.'

'Led by qualified specialists and supported by local volunteers, these regular social groups improve well-being and reduce isolation for whole families. New friendships are often formed and people who attend leave the sessions feeling like they have a better quality of life.'

Source: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=2019&pageNumber=3

Our survey respondents were positive about providing as well as receiving peer support: 79 per cent said they were ‘somewhat’ or ‘very’ interested in being involved in local organisations that provide support to others with the same condition (see question 13 in appendix B).

Peer support is low-cost, as it is generally delivered online or through civil society groups, and because it relies on patients, families and the wider community volunteering their time. Peer support mechanism can be set up quickly and locally, and can easily change as demand changes.

Importantly, peer support is associated with improved health outcomes in all the most common long-term conditions: patients who use peer support are more stable, less prone to exacerbation and show improvements in core clinical indicators (Nesta 2013). Nesta estimates that peer support could lead to a reduction in the cost of delivering healthcare of around 7 per cent, due to decreased A&E attendances, reduced hospital admissions, shorter stays, and decreased patient attendances (ibid).

A third of our survey respondents (33 per cent) thought that support from other patients would reduce the likelihood that they would need to use clinical services like A&E and GPs (see figure 4.3).

We recognise that peer-to-peer support may not always be seen as ‘credible’ by some health professionals and some patients, so may be under-used. The Mental Health Foundation (2012), among others, has sought to improve the credibility of peer support, and note that people may not always be able to access it easily, or that it may not be readily integrated with statutory service provision.

We also recognise that there are risks around over-reliance on peer-to-peer support, including the following examples.

- Increasing health inequalities, as some groups are less likely to participate in peer-to-peer support. Our survey found that older people were less likely than younger people to think that peer support would be useful. However, even where older people themselves may be sceptical about the benefits of peer support, those caring for them may value it.
- Similarly, online peer-to-peer support may disproportionately benefit certain groups, which means other groups may miss out (Wicks and Little 2013), perhaps because of a lower rate of internet use. It is therefore essential that non-online peer support mechanisms are provided.
- Harm may result from people discussing complex medical issues online and giving advice that goes against medical expertise. However, such a concern fails to recognise the fact that individuals – living with a condition day in, day out – develop their own expertise. Neither is it backed by evidence: the history of online health groups shows little recorded harm (Crocco et al 2002).

Despite these potential risks, we think that peer-to-peer support is an important aspect of available support, and should be expanded to ensure that more people can benefit from it.

Recommendation: Everyone diagnosed with a long-term condition should be able to access peer-to-peer support. Organisations operating in each local health economy – including voluntary sector organisations - should work together to enable the provision of peer-to-peer support mechanisms in communities, as well as enabling access to online peer-to-peer support.

4.4 Healthcare plans, with shared decision-making between healthcare professionals and patients, would empower patients further

Healthcare plans are a useful tool to help ensure that patients' healthcare support meets their needs, and to enable patients to become expert day-to-day self-managers of their conditions.

NHS Choices states that 'everyone with a long-term condition can have a care plan if they want one'.⁵⁰ However, this was not always our survey respondents' experience.

'I asked for a care plan on more than one occasion, but it has not been forthcoming.'

HealthUnlocked survey respondent

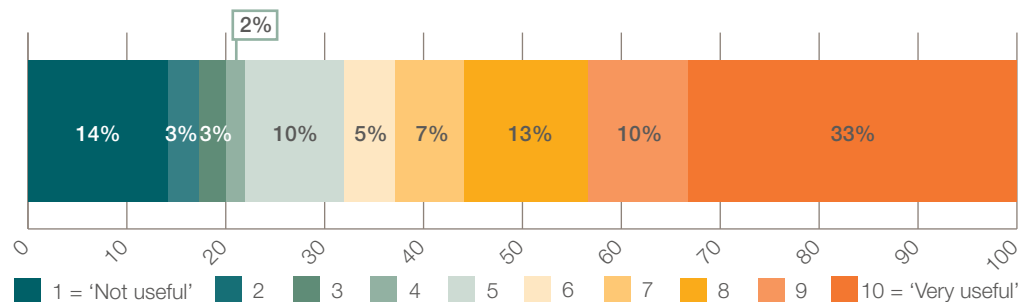
'You have to get the baseline treatment right first, and that just isn't happening for me, especially when I have to wait eight months between specialist appointments and still don't have a treatment or care plan.'

HealthUnlocked survey respondent

Over half (56 per cent) of our survey respondents – whether or not they had been offered one – thought that a care plan would help in the day-to-day management of their conditions.⁵¹ People who used clinical services most often were more positive about care plans than those who used services less frequently.

Figure 4.8

Breakdown of responses to the 'care plan' option in question 9, 'On a scale of 1–10 how useful would the following services be for the day-to-day management of your health condition? (where one is not useful and 10 is very useful)'



Note: the above is a detail from figure 4.1.

Respondents who said that they had been offered a care plan were much more likely to be satisfied with the day-to-day management of their health condition: 91 per cent⁵² were 'somewhat' or 'very' satisfied, compared to 63 per cent for all respondents (see figure 3.5).

Healthcare plans will also be key to ensuring that health and social care services are joined up at the front line in order to treat people with 'whole person care'⁵³ and personalised services. As IPPR has argued elsewhere (Bickerstaffe 2013a), it is important that both physical and mental conditions are captured. It is also crucial

50 <http://www.nhs.uk/Planners/Yourhealth/Pages/Careplan.aspx>

51 That is, gave it a score of eight or more on a 10-point scale, from 'not useful' (1) to 'very useful', in answer to question 9 – see figure 4.1.

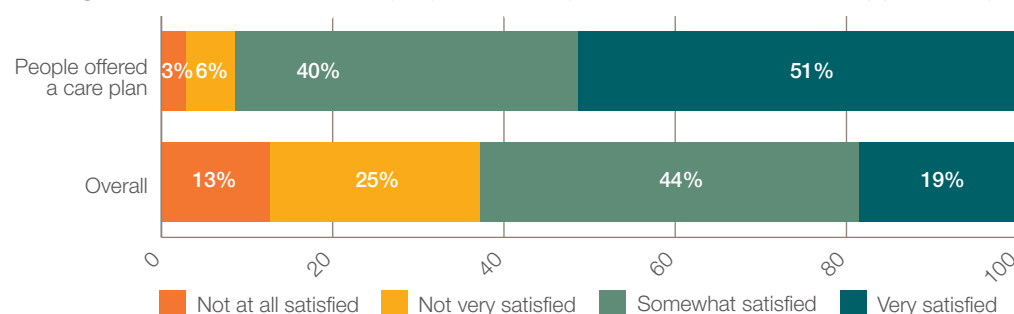
52 Questions 4 and 6 – see figure 3.5

53 That is, care that considers their physical and mental health needs, plus any social care needs, together.

that where people also have identified social care needs, healthcare plans address these too, with input from relevant professionals across the health and social care system. Plans should also consider wider factors that affect people's health – for example, whether someone with chronic obstructive pulmonary disease lives in damp housing.⁵⁴ This would mean that healthcare plans could be used by patients as a tool in interactions with providers of non-healthcare services that affect their health.

Figure 4.9

People offered a care plan were far more likely to be satisfied with the day to day management of their condition (responses to questions 4 and 6 – see appendix B)



Healthcare plans should not be devised by healthcare professionals alone – patients (and their carers) should be strongly involved. We argued in chapter 2 that people with long-term conditions are the experts on the effect of their condition(s) on their wellbeing and the lives they want to lead, and expert in the effects of the interplay between multiple conditions, and on the effects that their housing, income and family situation have on how able they are to manage. We also argued that we need to move to a model where this expertise is recognised and used to inform decisions about overarching care management strategies and plans, where healthcare professionals and patients develop a mutual understanding and trust of each other, working in partnership. Our survey respondents supported this argument.

'I want to be in control of my own life and be involved in any health care plan for myself.'

HealthUnlocked survey respondent

'The service could be improved if doctors were to listen to the patient and not sometimes treat them as stupid. We know our bodies better than them, and know when something isn't right.'

HealthUnlocked survey respondent

Such a system will require healthcare professionals to engage patients in shared decision-making – a two-way process that draws on the expertise of the clinician and the patient to make decisions about their care. Coulter and Collins (2011) have identified three essential components of shared decision-making.

- The provision of reliable, balanced, evidence-based information outlining treatment, care or support options, outcomes and uncertainties.
- Decision support counselling with a clinician or health coach to clarify options and preferences.
- A system for recording, communicating and implementing the patient's preferences.

⁵⁴ The role of policies affecting the wider determinants of health will be considered in a subsequent IPPR report.

If healthcare planning is to be a two-way process, it makes sense for healthcare plans to include goals and responsibilities for patients to meet, as well as plans for healthcare services. These might concern taking medication as prescribed,⁵⁵ following therapy regimes, or making lifestyle changes. There is perhaps also an argument for patients to be able to demonstrate objectively to healthcare professionals that they have expertise in self-management.

Healthcare plans will be a key tool for people performing a named contact role or a care coordination role; for one thing, they will enable them to hold the system to account, on behalf of patients, for delivering agreed services. We welcome the objective set out in the NHS Mandate that ‘everyone with long-term conditions, including people with mental health problems, will be offered a personalised care plan that reflects their preferences and agreed decisions’⁵⁶ by April 2015. We recommend that these plans are developed in partnership with people, with equity of input from patients and health professionals.

Recommendation: Everyone with a diagnosed long-term condition should be guaranteed a healthcare plan covering their physical health, mental health and social care needs, into which they have substantial input and which they develop in partnership with – and jointly agree with – their healthcare professional or care coordinator. Healthcare plans should include peer-to-peer support and assistive technology as a matter of course.

4.5 Personal health budgets can further empower people

‘My quality of life would improve vastly if I had access to better professional care and support, and the treatment best suited to me, rather than the GP’s budget.’

HealthUnlocked survey respondent

We have argued above that people with long-term conditions should have healthcare plans which set out how their overarching health and social care needs will be addressed. Many people will want the healthcare services to take the lead in arranging for services to be provided. Others will want more control, to have more of a role in choosing their specific services and in making arrangements within specified budgets. They could do this by means of a personal health budget, which is a valuable mechanism for shifting power to people who use public services.

Social care personal budgets

Personal budgets for social care are much better established than personal health budgets. Social care personal budgets arose from the disability rights movement, and are firmly rooted in the principles of self-determination and independent living. For adults with disabilities, for example, the use of direct payments and then personal budgets has enabled a shift away from institutional care and towards personalised support.

This ability to decide exactly how a budget is spent – and, if people choose to receive direct payments, directly spending that budget – represents a clear shift of power towards users, although its success depends on the right support being available and professionals being engaged.

Some people choose to spend their social care personal budget on a personal assistant, with whom a consistent relationship can be formed and who can provide care and support that fits around people use of direct payments and then personal budgets has enabled less flexible care arrangements.

55 Up to 50 per cent of medicines are not taken as intended by the prescriber (Howard 2014).

56 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf

What is a personal health budget?

NHS England defines a personal health budget, and the things that it can be spent on, as follows.

A personal health budget is an amount of money to support the identified healthcare and wellbeing needs of an individual, which is planned and agreed between the individual, or their representative, and the local clinical commissioning group (CCG). 'A personal health budget can be spent on any care or services that are set out in the care and support plan that has been put together with the NHS team or voluntary organisation working with the person – and this needs to be agreed by the CCG (clinical commissioning group).

There are things that it would not be right for the government to fund such as alcohol, tobacco, gambling or debt repayment, or anything that is illegal.

A personal health budget cannot be used to buy emergency care – for example, if someone in receipt of a personal health budget had an accident, they would go to A&E like everyone else – they would not use their personal health budget to arrange for it to be x-rayed, set or plastered.

A personal health budget also cannot buy primary care services such as seeing a GP or dental treatment. Other services recommended by a GP, like physiotherapy, could be included.

The budget may be:

- *a notional budget (an allocated amount that is agreed with the patient but no money is given directly to the patient; the NHS arranges the agreed care and support within that budget)*
- *an actual budget transferred from the NHS to a third party, which then arranges the agreed care and support within the budget*
- *an actual budget transferred from the NHS to the patient, who then arranges the agreed care and support within the budget.*

Source: Excerpted from <http://www.personalhealthbudgets.england.nhs.uk/About/faqs/>

A DoH-commissioned evaluation of personal health budget pilots found that personal health budgets were cost-effective and were 'associated with a significant improvement in the care-related quality of life and psychological well-being of patients' (Forder et al 2012). These effects were particularly evident where the budgets were relatively high-value – for example, when people had relatively high levels of need. However, they 'did not appear to have an impact on the *health* status *per se* over the 12 month follow up period' (ibid). The evaluation also found an overall reduction in the number of visits to hospital among people with a personal health budget.

Our own survey uncovered some appetite for personal health budgets: over a quarter (27 per cent) of respondents indicated that they would be interested in having a personal health budget (see figure 4.10), and over a third (37 per cent) said they would be interested in receiving a type of direct payment to allow them to buy services directly themselves (see figure 4.11).⁵⁷ This relatively low level of interest, relative to interest in other options (see figure 4.1), may indicate that personal health budgets are simply not right for everyone. However, many respondents had never heard of personal health budgets, and in the absence of any information about them, many were ambivalent both about them and about receiving payment directly.

57 The question asked whether people would like to receive the money on a prepaid card – see figure 4.11.

Figure 4.10

Responses to question 11, 'Would you be interested in a "personal budget" for managing your health with your medical team?'

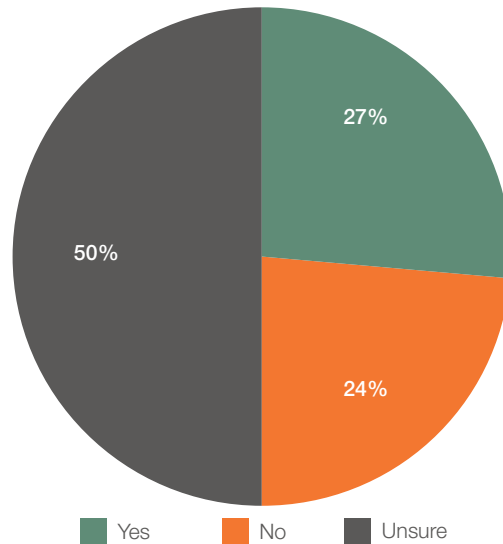
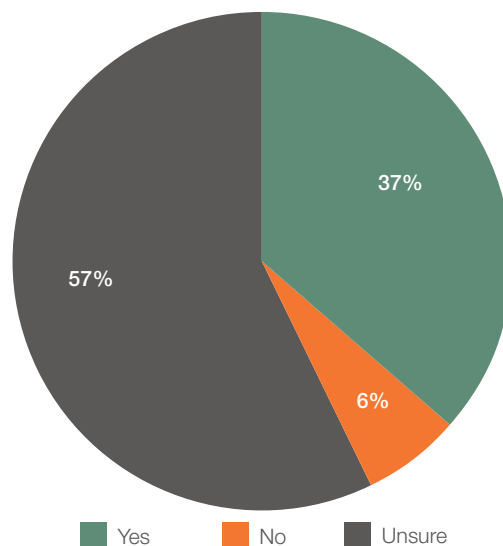


Figure 4.11

Responses to question 12, 'Would you be interested in receiving this money on a prepaid debit card so that you could buy the services and support you wanted yourself?'



Personal health budgets are currently for people eligible for NHS Continuing Healthcare (people who are not in hospital but who are assessed as having complex and substantial ongoing healthcare needs).⁵⁸ These people currently number around 60,000 (HSCIC 2014). People in this group have, since April 2014, had the right to ask for a personal health budget, and from October 2014 will have the right to *have* a personal health budget. Local NHS organisations are also able to offer them to

⁵⁸ See <http://www.personalhealthbudgets.england.nhs.uk/About/faqs/>

other people if they wish, and the NHS Mandate says that ‘patients who could benefit will have the option to hold their own personal health budget as a way to have more control over their care’.

We believe that personal health budgets should be offered to more people who are diagnosed with a long-term condition. No one should be forced to have one, but everyone with a long-term condition should be made aware of them and their potential benefits. It would be sensible to initially roll out personal health budgets to people who already have personal budgets for social care, and to combine those two budgets into one integrated health and social care personal budget. It would also be sensible to, at the same time, roll out personal health budgets to people with higher health needs: evidence from a DoH-commissioned evaluation (Forder et al 2012) shows that people with higher health needs (and so a larger budget) benefit more than others. It is notable that as yet there is little available evidence regarding whether personal health budgets are more or less suitable for specific conditions. In future, personal health budgets may be a suitable vehicle for personalised medicines – treatment that is, for example, tailored to people’s individual genetic make-ups.

For personal health budgets to work, people need to have full information about, and access to the choices available. The services to choose between should be high-quality, and people should be enabled to make supported, informed decisions. The budgets allocated should be aligned to the healthcare plans described in the previous section, and lessons will need to be learned from the roll-out of social care budgets in terms of how to ensure people have access to a range of high-quality services.

We welcome NHS England’s recent announcement of ‘a new Integrated Personal Commissioning (IPC) programme, which will for the first time blend comprehensive health and social care funding for individuals, and allow them to direct how it is used’, with an integrated, ‘year of care’ capitated payment model.⁵⁹ It makes sense for personal health budgets to be joined up with social care personal budgets into a single budget, as it will make it easier to address all health and social care needs in an integrated way. Such budgets create the potential for truly coordinated and personalised care – for example, integrated budgets could be used to hire a personal assistant who can carry out social care and healthcare tasks, replacing separate visits from different providers. For this to work, the wider system will need to change, including the adoption of integrated healthcare planning conducted in partnership between patients and healthcare providers (as mentioned earlier), as well as wider changes to the system and workforce which IPPR will explore in a subsequent report.

Recommendation: The offer of integrated personal health and social care budgets, based on people’s agreed healthcare plans, should be rolled out further, prioritising people who already have personal budgets for social care, and those with high levels of health needs.

4.6 Enabling technology can empower and support patients, but there is limited enthusiasm for it

New technologies make shifting power to patients, families and communities possible in a way that it has not been in the past.

We have already explored several ways in which technology can play a role in self-management.

59 For more information go to <http://www.england.nhs.uk/2014/07/09/ipc-prog/>

- Access to information – the internet has opened up a wealth of health information to the public that was not previously easy to access.
- Social networks – people who use the internet can participate in online exchanges, particularly with people with similar conditions, which hugely expands their potential social network.
- Communication with healthcare teams – such as providing a day-to-day contact point for health queries or booking appointments.

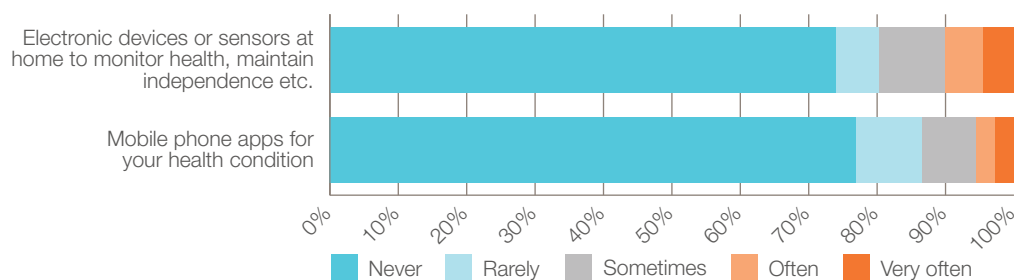
Telehealth and telecare – including apps and devices such as sensors in the home to detect falls or devices to monitor glucose levels in the blood – offer a different means for technology to empower people with long-term conditions by allowing them to monitor and treat their conditions at home and remain independent for longer. There is scope for greater use of technology to reduce people’s need for face-to-face contact with health professionals, which could benefit patients as well as create savings: every 1-percentage-point reduction in face-to-face contact is estimated to save the NHS up to £200 million (DoH and NHS 2011).

There are growing numbers and types of apps and devices for supporting independence and monitoring health; these can be standalone, linked to people’s phones or connected to the internet.

Of our survey respondents – who, as users of a health social networking site, we might reasonably assume to be more likely to be earlier adopters of technology than others – showed limited interest in apps and devices. Only one in seven people (14 per cent) used condition-specific apps at least sometimes, and three quarters (74 per cent) never used electronic devices to monitor their health at home or maintain independence (see figure 4.12). The lack of take-up among our respondents may be due to their conditions not being well catered-for by existing apps and devices. It may also be that, as a demographic, people with long-term health conditions make less use of apps and electronic devices than others. Or it may be because apps and devices are a relatively new innovation so people – both patients and healthcare professionals – do not yet view them as a normal part of healthcare.

Figure 4.12

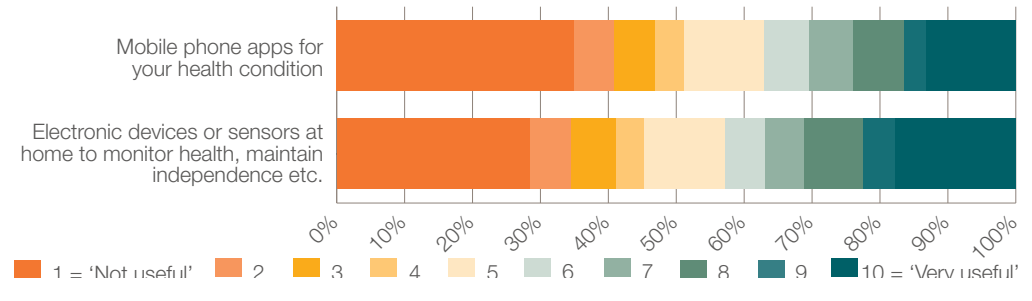
Responses to question 8, ‘How often do you use devices and apps to improve the day-to-day management of your health?’



When asked whether they thought apps or devices would be useful in the day-to-day management of their condition, only around a quarter (24 per cent) of our respondents thought condition-specific apps would be useful, and less than a third of them (31 per cent) thought electronic devices to monitor health and maintain independence might be useful.

Figure 4.13

Responses to question 9, 'How useful would devices and apps be for the day-to-day management of your health condition?'



This suggests that people with long-term conditions – even those like the people we surveyed, who are actively engaged in using the internet to help them manage their health conditions – are generally not yet aware or convinced of the relevance of telehealth and telecare and the benefits that they might bring.

NHS England is running the 3millionlives programme,⁶⁰ an initiative to help three million people with long-term conditions or social care needs to benefit from telehealth, telecare, telemedicine and telecoaching.

*'Telehealth and telecare have been around for more than 20 years, yet they are still in their infancy in terms of wide scale adoption. If technology is to deliver the benefits it promises, the NHS will need to redesign the pathways of care that are provided for people with long-term conditions. It needs to do this at a scale and pace that has not been seen before.'*⁶¹

Source: <http://3millionlives.innovation.nhs.uk/pg/dashboard>

The 3millionlives programme is rightly pursuing a partnership approach between government, industry, the NHS, social care, patients and the voluntary sector. A crucial part of its roll-out will be to generate interest among people with long-term conditions who might benefit from it. This will need to include equipping front-line health professionals with the knowledge and skills necessary to advise and coach patients on options and potential health benefits, and to build these into healthcare plans.

As IPPR has noted previously (Bickerstaffe 2013b), government has a key role to play in encouraging and enabling innovation in new technologies.

'Strong leadership from within the public sector is crucial to overcoming the resistance that practitioners and managers often show initially...'

'There are three specific areas where government should support action.'

- *Demonstrating impact: government should team up with a digital specialist to produce guidelines on evidencing quality improvements and cost-effectiveness of projects in this area.*
- *Overcoming resistance: government should ensure that the potential of digital technology is built into training for public service workers.*
- *Harnessing user demand: government should raise awareness among users and practitioners of the innovations that are available for them to use directly and free of charge.'*

Source: Bickerstaffe 2013b

60 See <http://www.england.nhs.uk/2013/11/15/new-tech-imprv-ht-serv/>

61 For more information go to <http://3millionlives.innovation.nhs.uk/pg/dashboard>

We suggest that front-line health professionals be trained and expected to make patients aware of technologies that could potentially support them to self-manage their conditions, to encourage uptake of them, and to help more people self-manage their conditions and stay living independently at home for longer.

Recommendation: Healthcare plans should, as a matter of routine, contain consideration of relevant technology, such as telehealth and telecare options.

4.7 Summary

If patients are to have greater control, they must have access to the information and support they need – such as having a named contact, access to good-quality data and information (including easy access to their own medical records), support from others in similar situations, healthcare plans and personal budgets, and enabling technology. Different people may find different types of support more or less useful, but it is important that people have access to the support they need. It is important to note that we have discussed patients’ – rather than carers’ – wishes in this report, as our survey was of people with long-term conditions themselves. However, we expect similar principles to hold true for carers of people with long-term conditions.

CONCLUSION, SUMMARY OF RECOMMENDATIONS, AND NEXT STEPS

Conclusion

The high number of people in the UK who have long-term conditions means that we need to expect and equip people with long-term conditions to have greater control over the services they receive, and greater empowerment in their day-to-day self-management of their conditions. This approach has the potential to drive positive health outcomes, helping people stay healthier for longer, which is not only better for patients but can also lead to reduced demand on healthcare services. People want more control, and to be recognised as experts in their own conditions, provided that they have what they need to feel empowered: a named contact, better data and information (including easy access to their own medical records), support from others in similar situations, healthcare plans, and, for some people, personal budgets and enabling technology.

Summary of recommendations

A named contact

1. People with long-term conditions should be offered a single, named point of contact for day-to-day queries about their health, healthcare and care coordination if they want one, and should be able to contact them easily and directly.

Ownership of medical records, and better information and advice

2. Patients should legally own their medical records, which should continue to be housed in the NHS, and they should be guaranteed free access to their medical records on demand. In the interim, a 'patient's healthcare log', which is held by patients and which details their medical and clinical histories, should be considered.
3. It should be guaranteed that everyone diagnosed with a long-term condition – at the point of diagnosis and regularly thereafter – is offered information, advice and coaching about how best to self-manage their condition. The National Institute for Health and Care Excellence (NICE) should develop patient-friendly equivalents of each clinical guidance note relating to long-term conditions, including condition-specific checklists for patients to use to ensure that they are getting the services they need.

Peer support

4. Everyone diagnosed with a long-term condition should be able to access peer-to-peer support. Organisations operating in each local health economy – including voluntary sector organisations – should work together to enable the provision of peer-to-peer support mechanisms in communities, as well as enabling access to online peer-to-peer support.

Healthcare plans

5. Everyone with a diagnosed long-term condition should be guaranteed a healthcare plan covering their physical health, mental health and social care needs, into which they have substantial input and which they develop in partnership – and jointly agree – with their healthcare professional or care coordinator. Healthcare plans should include peer-to-peer support and assistive technology as a matter of course.

Personal health budgets

6. The offer of integrated personal health and social care budgets, based on people's agreed healthcare plans, should be rolled out further, prioritising people who already have personal budgets for social care, and those with high levels of health needs.

Next steps

In a subsequent report, IPPR will explore what the healthcare system would look like if empowering patients were the key driver for system design – and what needs to change to deliver that system.

This report has purposely focused on what 'good' looks like from the point of view of people with long-term conditions, rather than on system reform, in order to put patients truly at the centre. With this groundwork done, the system changes we will propose in our next report on this topic will be truly patient-centred, in order to achieve the twin aims we outlined above – namely, that people with long-term health conditions should:

- have greater control over the services they receive
- having greater empowerment and expertise in their day-to-day self-management of their condition(s).

The healthcare system will need to change in the following respects.

- The way the front-line workforce is organised, trained, recruited, rewarded and appraised must be changed, to enable and encourage the development of empowering and partnering relationships with patients.
- We must ask what health education is needed to empower people to make informed decisions, and how relevant technology might be used more effectively.
- In terms of decision-making and commissioning, we need to consider how arrangements can be joined up at the strategic, decision-making level in order to empower people; how the wider system is included; and how patients' voices can influence decisions.
- With respect to funding mechanisms and incentives, we must examine how greater pooling of funding at the local level might help people better self-manage their conditions and get personalised and preventative services, so that people are more empowered and healthier for longer. This must include looking at capitated and long-term budgets.
- The role of national institutions and policies – including patient guarantees, guidance, information and advice, support for technology, and providing access to medical records – must be reconsidered.
- Finally, we must also consider the wider system, in terms of how national outcome measures could promote empowerment, and how wider determinants that affect people's health should be considered.

IPPR will explore these themes in a subsequent report.

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APPENDIX A

SURVEY METHODOLOGY

IPPR asked HealthUnlocked, Europe's largest social network for health, to survey its users for us.

Over two million people visit HealthUnlocked every month in order to learn from the health experiences of others. Its communities of patients are moderated by almost 500 third-sector patient organisations, which provide quality assurance and moderation of users' shared experiences and stories. It is a free online platform which is based in the UK (and embedded in NHS Choices) but is also used in Spanish and Portuguese, and has partnership organisations in over 20 countries and online visitors from almost every nation.

In launching this survey across a population of people who use a health social networking website, we made a conscious effort to understand the landscape from the perspectives of people who may already be actively seeking out information and support relating to their conditions and healthcare, and who are, by definition, digitally engaged. Implicitly, it does not account for the significant minority of digitally excluded people, for whom access to or use of the internet has not yet become a part of any component of their lives, let alone their health.

The survey presented an opportunity to test existing attitudes and experiences alongside a set of new ideas aimed at benefitting patients by putting them more 'in control' – that is, by giving them a more central and independent role in their care. This might be achieved by resourcing better self-management at home, allowing a more participative and connected relationship with clinicians, or fostering a more proactive role in service design and delivery. These concepts are tested in the survey.

The results reported here come from a survey undertaken in March 2014 of 2,623 adults living in the UK with one or more ongoing mental or physical health conditions, and who use the HealthUnlocked online social network. 55,740 people received the invitation to participate in the survey in a message sent through their HealthUnlocked user profile.

APPENDIX B

SURVEY QUESTIONNAIRE

'User Power in Health and Social Care'

Dear HealthUnlocked member,

Do you have an ongoing health condition?

Are you resident in the UK?

If you answered 'yes' to these two questions then we'd like to invite you to participate in a survey for the Institute for Public Policy Research (IPPR),⁶² a non-profit 'think-tank' focussed on public policies such as education and health.

IPPR are undertaking a study that aims to better understand people's beliefs and understandings about topics related to user power in health and social care.

Before you decide whether you want to take part, it is important for you to understand why the survey is being done and what your participation will involve. Please take time to read the following information carefully:

- The survey is being funded by IPPR and implemented in partnership with HealthUnlocked.
- All information you provide will be anonymous and treated in the strictest confidence and according to legal and ethical guidelines of the UK Data Protection Act 1998.
- You will be able to find the results of this study at the IPPR website.⁶³
- If you decide to take part you are still free to withdraw at any time and without giving a reason. However, as data collection is anonymous, once data has been sent that information cannot be withdrawn.

If you have any questions or require more information about this study, please email us at research@healthunlocked.com.

The survey should only take about 10 minutes to complete.

Question 1. Do you have an ongoing health condition?

- Yes, physical health condition (e.g. diabetes, arthritis)
- Yes, mental health condition (e.g. depression, anxiety)
- Yes, both physical and mental health conditions
- No

2. Are you based in the UK?

- Yes
- No

3. Roughly how many years has it been since you were diagnosed with your (main) health condition?

.....

62 <http://www.ippr.org/>

63 <http://www.ippr.org/>

4. In general how satisfied are you with the day-to-day management of your (main) health condition?

- Not at all satisfied
- Not very satisfied
- Somewhat satisfied
- Very satisfied

Comment here:.....

5. Roughly how many times in the last 12 months have you made use of clinical services (hospital, A&E, clinic, GP etc.)?

.....

6. When you were first diagnosed were you offered any of the below by your medical team? (Select any that apply.)

- Information (e.g. leaflets/websites) about your condition
- Information about local services and support
- A way of connecting with other people with the same condition for advice
- Coaching or courses about how to manage your condition
- Apps or websites that help you manage your condition day-to-day
- Devices to help you monitor your condition at home
- A named individual who you can contact directly about any aspect of your care
- A care plan⁶⁴
- A personal budget⁶⁵
- None of the above

Comment here:.....

7. In addition to HealthUnlocked, how often do you look for information about your health outside your medical team?

	Never	Rarely	Sometimes	Often	Very often
Search engines (e.g. Google)					
NHS Choices website					
Voluntary patient organisations (e.g. Macmillan website/phone, etc.)					
Pharmacies					
Libraries					

64 A care plan is a part of your medical notes introduced in recent years. It's where you make decisions or note down goals together with your medical team. You can sometimes keep a copy for yourself at home. Everyone with a long-term condition in the UK can have a care plan if they want one.

65 A personal budget is an amount of money to support your health and/or social care needs, planned and agreed between you and your care team. In England, they have been available to people receiving council-funded social care for several years, and they are being introduced by the NHS to help people manage their healthcare in a way that suits them.

8. How often do you use technology to improve the day-to-day management of your health?

	Never	Rarely	Sometimes	Often	Very often
HealthUnlocked					
Other social networking (Twitter, Facebook, other)					
Online communication with your care team (e.g. emailing, online appointment booking, etc.)					
Searching online for information about your health condition					
Searching online for information about local services and support					
Mobile phone apps for your health condition					
Electronic devices or sensors at home to monitor health, maintain independence, etc.					

Comment here:.....

9. On a scale of 1–10, how useful would the following services be for the day-to-day management of your health condition? (Where one is not useful and 10 is very useful.)

- Coaching or education about how to manage your condition
- Mobile phone apps for your health condition
- Electronic devices or sensors at home to monitor health, maintain independence or otherwise
- Support/advice from other patients with the same condition
- A named individual who you can contact directly about any aspect of your care
- Access to your NHS/medical record
- A care plan⁶⁶
- A personal budget.⁶⁷

10. If you were given a named contact to telephone/email directly about day-to-day health issues, how useful do you think the following would be?

	Not useful	A little useful	Somewhat useful	Very useful
Someone from a related patient organisation				
A healthcare professional (nurse, psychologist, etc.)				
Someone who knows all about local services and support (with no health qualification)				
An experienced patient with the same condition				

Comment here:.....

⁶⁶ See footnote to question 6, above.

⁶⁷ See footnote to question 6, above.

11. Would you be interested in a ‘personal budget’ for managing your health with your medical team?

- Yes
- No
- Unsure

Comment here:.....

12. Would you be interested in receiving this money on a prepaid debit card so that you could buy the services and support you wanted yourself?

- Yes
- No
- Unsure

Comment here:.....

13. How interested are you in any of the below (regarding planning and delivery of your local health services)?

	Not at all interested	Not very interested	Somewhat interested	Very interested
Being involved in local organisations that provide support to others with the same condition				
Responding to consultations from the NHS or your local authority				
Becoming a member of boards of local health and care organisations				
Becoming a member of a Foundation Trust (hospital)				
Working with local NHS and/or local authority to decide what services and support to commission (pay for)				

14. Do you agree with the following statement? ‘If you were better supported, more of your day-to-day health could be managed independently at home.’

- Strongly disagree
- Somewhat disagree
- Somewhat agree
- Strongly agree

Comment here:.....

15. Would any of the following reduce the likelihood that you need to use clinical services (hospital, A&E, GP, etc.)?

- Coaching on managing your condition better at home
- Support from other patients (e.g. through HealthUnlocked)
- Having a named contact for telephone support and advice
- Involvement in deciding how money is spent on your health (personal budget)

Other (please specify):.....

16. Do you support the idea of trying to manage more ongoing health problems at home?

- Yes
- No
- Unsure

Comment here:.....

17. Are there any ways in which the services and support that you use could be improved to put you more in control of any day-to-day health challenges?

.....

18. Which of the following best describes you?

- Female
- Male

19. What is your age group?

- 16–19
- 20–29
- 30–39
- 40–49
- 50–59
- 60–69
- 70 and over

20. Which of the following best describes your current activity?

- Student
- Full-time paid employee/self-employed
- Unemployed and seeking work
- Looking after home/family
- Temporarily sick/disabled
- Permanently sick/disabled
- Retired

21. Which of the following best represents your total HOUSEHOLD income in the last 12 months (e.g. earnings, benefits, pensions, and interest from savings)?

- Under £15,000
- £15,000–£19,999
- £20,000–£29,999
- £30,000–£39,999
- £40,000–£49,999
- £50,000–£74,999
- £75,000–£99,999
- £100,000 or more
- No income

22. Which of the following best describes the highest level of education qualification you achieved?

- Degree-level qualification (or equivalent)
- Higher educational qualification below degree level
- A-Levels or Highers
- ONC/National Level BTEC
- O Level or GCSE-equivalent (grade A–C)
- GCSE grade D–G or CSE grade 2–5 or Standard Grade level 4–6
- Other qualifications (including foreign qualifications below degree level)
- No formal qualifications

APPENDIX C

PROJECT ADVISORY BOARD

The authors would like to thank IPPR's 'Health – Fit for the Future' programme advisory board, whose members gave direction to the scope of this report and provided useful insights and guidance.

- Alan Milburn (chair), former secretary of state for health
- Stephen Dorrell MP, former secretary of state for health and chair of the House of Commons health select committee
- John Pugh MP, former co-chair of the Liberal Democrat parliamentary committee for health and social care
- Professor Lord Ara Darzi, director, Institute of Global Health Innovation, Imperial College
- Dr Jane Roberts, consultant psychiatrist and IPPR trustee
- Dr Sam Barrell, chief clinical officer, South Devon and Torbay CCG
- Imelda Redmond, director of policy and public affairs, Marie Curie Cancer Care
- Michael Macdonnell, head of strategy, NHS England
- Dr Axel Heitmuller, director of strategy and commerce, Imperial College Health Partners
- Dr Chai Patel, Chair, HC-One
- Dr Ruth McKernan, senior vice president, Pfizer UK
- George McNamara, head of policy, Alzheimer's Society
- Kate Tillett, executive director external affairs, MSD
- Emil Peters, vice president and managing director, Cerner Limited