Design Council

RED PAPER 01

HEALTH: Co-creating Services

Hilary Cottam and Charles Leadbeater

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This paper looks at the new challenges facing public services, taking health as a case study. Chronic disease presents a new and growing health challenge. This paper argues that reform to the health services currently on offer cannot address either the management of chronic diseases or the broader lifestyle issues that might promote better health. We argue for a new approach which we call co-creation since a set of new relationships between users, workers and professionals lies at its heart. We set out this model. Many of the seeds of this new approach can be found within the current system. Communities of the kind we envisage are well developed in software and other fields. We suggest ways in which we could build on these open systems to foster a new form of co-created public service. Our ideas should be considered as work in progress: we hope to develop our model further as we test our approach in practice with partners in Kent and Bolton.

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The Design Council enhances prosperity and well-being in the UK by campaigning for the best use of design in business and the public sector.

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The Limits to Public Service Reform

Current approaches to public service reform are reaching their limits. Service providers bemoan central targets that drive performance. Professionals complain about poor pay and heavy workloads. Users complain of poor quality, lack of personalisation and services that do not join up. Ministers and senior civil servants worry about improving large and complex systems that are difficult to control. Innovation is widespread but difficult to propagate. Attempts to make the public service machine work harder produce their own backlash.

More importantly in the long run, the issues addressed by public services are themselves in flux and changing. A wide range of prominent issues, including the environment, crime, and public health concerns such as smoking and obesity, cannot be adequately addressed by traditional services. Effective responses must encourage new norms of behaviour within society, developing approaches in which those who use services become involved in their design and delivery. Addressing these issues will require more than better services. Developing new responses will require social creativity, activating knowledge networks, resources and imagination across society not just within the public service professions and institutions.

These are issues which many progressive professionals are attempting to grapple with on a daily basis. We look at some of the resulting important innovations within this paper. At the same time critical challenges remain as to how professionals relate to and work with a public who are increasingly demanding more than improved choice or the potential to select a personal menu from the reformed solutions or services currently on offer. There is a demand for new services and approaches that are in step with the economic and social structures, desires and practices that increasingly prevail.

In this paper we consider health as a case study. Reformed versions of top down, institutionalised services cannot do much to tackle either the escalating chronic disease burden or the public health issues which

might prevent the onset of such diseases through encouraging different lifestyles and behaviours. New professional roles are needed with complementary developments for front line workers and improved interfaces for service users.

We argue that we need a different way forward: not further incremental innovation but rather radical transformation and a new approach: co-created services. The need for prevention of illness and the promotion of health provides our starting point. We suggest that adequate solutions to these preventative issues have four key characteristics.

They will need to mobilise resources, know-how, effort and expertise **distributed** across communities and households, rather than turning solely to professional expertise located within institutions. Distributed resources will be most effective when they can be used **collaboratively** to share ideas, provide mutual support and give voice to user needs. Solutions that are distributed but individualised may deepen inequality because only affluent people may be able to access them. Distributed resources need to be brought together to make an impact. Services will be **co-created** to address the particular needs and circumstances of individuals and communities. This requires interaction, participation and joint problem solving between users, workers and professionals. Distributed, collaborative and co-created services will require **radical organisational innovation** on a scale far beyond current models of public service reform.

Co-created services would differ in terms of their design, content, systems, their structures of delivery and their approach to resources. Co-created services are new, they are not merely new combinations of an existing offer. Critical elements of this new approach are already available. Creative professionals working within the system are pushing at the walls of the silos they work within, seeking new ways of working together and with users. Patient involvement programmes and mutual self-help groups are giving users a new voice in health care, as well as equipping them with skills and tools. Our proposals build on these approaches, which we are testing with our partners in Kent and Bolton. The lessons are not confined to health. They have huge potential across the public sector.

2
Health: New Challenges

The average person with diabetes spends about three hours a year with doctors, checking prescriptions and general health. However, they spend thousands of hours a year self-managing their condition. Traditional approaches to public service reform will give a diabetic more choice over their GP, a booked appointment or a patient's charter. Our argument is that it would be far more productive to focus on the thousands of hours the diabetic self-manages, through offering peer-to-peer support, better training and tools to cope with diabetes. It would be more productive still to encourage lifestyles, habits and the necessary supporting services that prevent an individual developing diabetes in the first place.

The nature of the health problem has changed. The 2002 Wanless report into the future of the NHS concludes that infectious diseases, the challenge of the 19th and 20th centuries, have given way to the prevalence of chronic disease. At the start of a new century, 12 million (approximately one in five Britons) suffers from a chronic disease. These numbers are likely to rise if factors influencing chronic conditions, such as diet, lifestyles, and smoking, are not addressed as the population ages. The incidence of diabetes for example, closely related to obesity, has risen to 1.8 million people in just eight years, costing the NHS £10 million a day.[1]

Take heart disease as another example. Between 1997 and 2002 there was a 23 per cent fall in deaths from diseases of the heart and circulatory system.[2] Much of this reduction was due to reforms to NHS cardiac services, particularly improved treatment of people who had suffered a heart attack. But much of the decline in heart disease deaths was due to lifestyle changes that swept the country 20 to 30 years earlier, when middle-class men in particular, gave up smoking in their millions. Part of the improvement came from the state providing services more effectively. But just as much came from millions of people changing the way they lived, which collectively produced the public good. In the first approach, users were patients in need of effective NHS services. In the second, the users were participants.

1 Diabetes UK 2004
2 Department of Health, March 2004

Traditional services, however they are reformed, are ill equipped to tackle the biggest health challenges we face. The current institutional approach based around the hospital infrastructure and its professional hierarchies and incentives is still organised to combat infectious disease. Supportive public health regulations are important, but rely on centralised control; they do not begin to encourage the active personal decision making which will ultimately promote good health. Chronic conditions, which are closely related to lifestyle need a wholly different approach—one which understands individual behaviours and motivations, involves the community and, critically, can address the socio-economic divisions which continue to underpin and determine lifestyle choices.

Within health, the emphasis on the community or the collective takes on a particular importance. There is increasing evidence that chronic disease is strongly related to networks and communities. Well-being is particularly dependent upon relationships: 'Independent lifestyles that are judged to be successful and fulfilling are generally determined by the extent and quality of relationships with others, together with the extent to which social cohesion provides economic, social and psychological security later in life.'[3]

In the new approaches we are urging—communities of co-creation—the key is to build up the knowledge and confidence of the users to take action themselves in new partnerships with professionals. Wanless argued that the future of health care in an era of chronic disease, would turn on the 'full engagement' of people in their own health care: 'there are potentially large gains to be made by refocusing the health service towards the promotion of good health and the prevention of illness.'[4] The key issue will not be the provision of more doctors and nurses, needed though they may be, but how effectively people are engaged in the responsible, collaborative maintenance of their own health.

3 Wistow, Eaddington and Godfrey 2004, see also Akinson 2004, Layard 2003, Power 2003, Stott 2000
4 Wanless 2002

3
Seeds of New Solutions

Of course what we are advocating is not entirely new. Nor are we suggesting that it is a complete solution: there will always be the need for effective, cost efficient hip replacements delivered by trained professionals. There have been a large number of preventative health initiatives from the creation of mass sewerage and refuse collection services in the 19th century onwards. More recently there have been a number of highly innovative initiatives aimed at exploring patient involvement more generally in the delivery of health care.[5]

Many health care professionals, especially those working close to the community, recognise that the silos of public service delivery do not serve them or their users well. They are straining to break out of these constraints and more traditional institutional frameworks.[6] Our approach is designed to help these innovative practitioners—who are often already working collaboratively alongside community workers, social services and education—to create better interfaces with innovative users who also want new services and solutions.

Innovative professionals can only achieve so much if they are working within traditional top down, departmentalised public services. User involvement will only get so far when connecting to services that are modified versions of traditional top down delivery models. Professionals and users could achieve a huge amount, working together, if they operate within a new framework. That is our aim.

Many of the seeds of the new approach we are recommending can be found within current systems.

Hospitals

The hospital system provides people with relief from conditions that can be treated, operated on or cured by providing timely access to professional skills. Doctors devise and implement solutions for us. Public service reform aims to make that process—admit, diagnose, prescribe, act, discharge—work as effectively as possible, maximising throughput and bed usage. Users are largely passive; they are waiting to be worked on.

5 Goodare and Lockwood 1999. See also Gerteis et al 1993 and the work of the Picker Institute www.pickereurope.org
6 See for example Moynihan and Smith *Too much medicine?* 2002, and the work of Dupuy 2003

Hospitals will continue to play a critical role in future health care, diagnosing conditions, providing emergency and acute care, carrying out surgery. Hospitals, however, cannot prevent the onset of chronic disease nor can they give the day-to-day support that people with chronic conditions need. Efficient hospitals are good at solving a problem once it is presented to them. Our aim must be to prevent more health problems before they even reach hospital. Hospitals provide access to medical knowledge. But most people with chronic conditions or lifestyle issues need non-medical advice and support as well.

Professional expertise will play a critical role in preventative and lifestyle programmes, but that expertise needs to support more distributed and co-created solutions, with medical professionals working alongside other disciplines and users.

People's experience of being in hospital is to say the least mixed. A 2001 UK survey of more than 2,000 recently discharged patients found that 20 per cent said that staff did not always treat them with respect and dignity, 29 per cent said doctors talked about them as if they were not there and 59 per cent said they were not given enough say in treatment decisions. The 572 Patient and Public Involvement Forums, one for each NHS Trust, are meant to provide a channel for engaging communities and users. However for many people the ethos of care that pervades the NHS is mixed with an ethos of paternalism which many patients find frustrating.[7]

The family

The largest health care provider in Britain is not the NHS but the family. Between 80 percent and 90 per cent of health incidents are dealt with at home, mainly by women, from administering Calpol to a child to long-term care for an elderly relative. The demand for home-based solutions is rising with the ageing population and the growth of chronic conditions. Technology—broadband communications, digital television, remote monitoring devices—is moving in that direction. A century ago we went to bath houses and laundries to get ourselves and our clothes clean. Now we use showers and washing machines at home. These days most medical technology is found in hospitals, the medical equivalent of the old bathhouse. It is not far-fetched to

7 Coulter 2001

assume that our homes will house far more medical technology alongside washing machines, televisions and computers.

Yet an influx of medical technology will not make good the declining capacity for the traditional family to deliver health care. A majority of women are in paid employment. Single households are the fastest growing group in the country. The household sector is under resourced to cope with the caring demands being placed upon it, unless public policy strengthens it. That is one of the aims of our approach.

The market

The market is a distributed system for meeting need by co-ordinating millions of decentralised decisions. Markets will be a part of co-created solutions. People turn to chemists for advice and treatments from headache cures to contraceptives and pregnancy testing kits. In low income areas the community pharmacy is often a vital source of advice and know-how, easier to access than the doctor's surgery. Demand for 'alternative' therapies from massage and osteopathy to herbal remedies and acupuncture is growing. An estimated 48 per cent of the UK population now purchase complementary medicine.[8] The growth of the private health and fitness industry is market driven. One estimate is that close to 100,000 people will join weight loss programmes this year, mainly run by private clinics.[9] Employers will be vital to preventative strategies. Some such as HBOS, the bank created by a merger between Halifax and Bank of Scotland, already offer employees subsidised 'Food for Thought' vouchers which can only be spent on healthy foods.

The market provides people with transactions: you go into a chemist to buy some cold relief. Managing long-term conditions or changing ingrained eating habits requires time, patience and commitment. It cannot be broken down into a series of transactions. The emotional and social support needed by someone caring for a relative with Alzheimers cannot be purchased from a chemist. Access to market-based services reflects inequalities in income. The poorest would benefit least, unless public policy makes sure that fitness and slimming programmes, are available in poor areas as well as middle-class areas. Poor people have more limited choice of foods, partly because some housing estates are food deserts, dominated by venders of fast and convenience foods.

8 UK Complementary and Alternative Medicines Market Research Report 2004
9 Revill 2004

Campaigns

The market is also the source of many of our most pressing health issues: fatty, sugary foods, excessive drinking and smoking. Most of the activities that make us unhealthy are marketed by companies that make a profit from the behaviour they encourage. Public policy is in competition with these advertising and marketing campaigns to influence people to make different decisions about eating, smoking and drinking.

That is why campaigns to change social norms, to make it less acceptable for people to smoke or drink, have been one of the main tools to promote healthier lifestyles. These campaigns infiltrate public values into the market through: regulation, for example to stop smoking in certain places; taxes to make it expensive to do things that are bad for your health; information campaigns to highlight risks; provision of help to people who want to change, for example, smoking cessation programmes. The BBC's *Fat Nation* campaign is a recent example of some of these tools being deployed to tackle obesity. There is huge scope for improved labelling on food, to make it easier for people to assess what is healthy for them. Campaigning approaches first applied to smoking are likely to be extended to sugar and salt.

However these campaigns have a number of limitations. They take a long time. It is difficult to run more than one campaign at once, to capture public attention. They place the responsibility on the individual when, as we have seen, the contributing factors and potential solutions are frequently collective. They often fail to reach or affect some groups, particularly poorer and poorly educated people, and so they run out of steam. The biggest declines in smoking, for example, have been among well-informed middle-class people. Smoking is now concentrated among younger people and people in lower socio-economic groups, where the rate of decline has slowed to a trickle. Also, health campaigns are not always as sophisticated in their approach as rival 'unhealthy' advertising campaigns, failing to understand the importance of both style and psychological motivation.

Often these campaigns seem based on mistaken assumptions about how people take decisions about their health. Someone with a chronic condition does not want to be broadcast to from on high. They want a far more personal, conversational, approach to sharing ideas and

know-how. Moreover, if someone finds out something is bad for their health, then acting rationally, they should change their behaviour. However most people who smoke know that it is bad for them, and many say they want to give up, but they cannot manage to do so. A complex set of competing psychological, social and environmental factors continue to support unhealthy practices. The key is whether individuals have the skills, confidence and tools to turn intentions into action. Public health campaigns need to be married to programmes that support people to take action.

Mutual self help

The health system is populated with support groups that do just that: they enable patients and carers to help one another. Being part of a social network—virtually any social network—is good for health. People who are isolated are far more likely to become ill and depressed. Collaborative self-help networks, often organised around specific conditions such as Alzheimers or diabetes, do more than this. They provide important support services for people: Age Concern, for example is an increasingly important provider of home care services. They provide advice for people on the non-medical aspects of coping with conditions: for instance, how to cope as a diabetic while travelling in China. They provide people with advice, expertise and most importantly emotional support. When someone is first diagnosed with Alzheimer's, it's likely that the Alzheimer's Society will be their first port of call for advice once they have left the doctor.

Collaborative self-care, often led by expert patients and carers is a vital complement to traditional health services. But these approaches are frequently seen as the poor relations of medical care. Mutual self-help has a long, and often hidden history, in health services. It also has huge potential.

The Long-Term Medical Conditions Alliance, an umbrella body for health charities, runs the Living Well project to develop high-quality lay led self-management programmes for people with long-term conditions. The Alliance runs courses for people co-ordinating self-management programmes. The Expert Patient Programme was set up by the Department of Health in April 2002 based on research which shows that people living with a chronic disease are often best placed

to know what they need in managing it. These approaches go back to techniques for the self-management of arthritis developed at Stanford University in California in the 1980s. Similar programmes have been developed for heart disease, stroke, depression, chronic pain, insomnia, sickle cell disease and multiple sclerosis.

In the UK, voluntary groups and charities, often working with innovative professionals, have pioneered self-management. Arthritis Care, the largest UK voluntary organisation working with people with arthritis, runs Challenging Arthritis, a six week self-management course which is run by local people with arthritis and equips people to deal with their pain more effectively by sharing ideas and experiences. The Alzheimer's Society has more than 25,000 members and 250 branches providing support for people with the condition. There is a long tradition of self-management with diabetes care, with an extensive infrastructure of self-help and support groups. Diabetes UK, the main charity, is the umbrella for more than 400 local and support groups.

However many of these initiatives tend to be niche activities, supported only by voluntary contributions. Most often these groups form around specific conditions—diabetes, arthritis—and appeal to people once they know they have a problem. A different strategy may be needed to attack more amorphous preventative and lifestyle issues such as eating.

Each of these approaches will provide part of the solution to the Wanless challenge. Access to professional medical knowledge will still be vital but it needs to be more distributed and mobilised to support self-management by users. The home will become more important as a site for health care, but only if the household can be supported with technology, services and advice. The market can provide easy-to-access, distributed services. Public campaigns help to change norms but often they do not touch those most in need and the key is to help people to turn good intentions into action. Self-help groups are highly effective but they are weakly connected to the larger system and tend to be organised around specific conditions. To make a larger impact they would need more resources to operate at scale.

We need strategies which are distributed, collaborative and co-created. To make that combination possible, we need radical organisational innovation. In the chapter that follows we take each of these in turn, setting out an alternative model.

4
The Co-creation Model

Preventative

A combination of rapid technological advance and increasing expectations is leading to trends in service demands which are outstripping potential economic growth: prevention is cheaper than cure. More important than these financial concerns however are the new public health challenges we have outlined. The growth in chronic disease demands new preventative strategies in the first instance, with the provision of new services of support and management for those who, despite all efforts to the contrary contract a chronic disease. The focus on prevention is thus a founding principle of the new approach.

The mantra of prevention is of course not new. First advocated by David Owen when he was Labour Minister in 1976, prevention has been a core theme in successive government white papers including those of 1977, 1991 (and is expected to be a theme in the forthcoming 2004 paper). Implementation has however proved notoriously difficult. It has been politically hard to shift either the professional focus or resources towards preventative strategies in the face of mounting waiting lists of acute patients. Furthermore, traditional strategies of mass health education through campaigns have found it difficult to motivate new behaviours and attitudes, even when a high level of understanding as to risks has been achieved, thus bringing in to question the validity of the preventative approach.

We are arguing not for prevention in the negative sense of avoidance and reduction in pressures on a service, but rather for the promotion of well-being, living well and successful ageing: factors which will affect the potential onset of chronic disease. We are suggesting that the core principles of distribution, collaboration and co-creation offer a new way forward.

Distributed resources

Responses to lifestyle health issues and chronic conditions will work only if resources, know-how, tools, advice and finance are distributed

out of institutions into communities and households to allow solutions to be assembled collectively and locally.

The front line of health care is not where professionals dispense their knowledge to patients but where people look after themselves, to prevent ill-health or cope with it. The biggest untapped resources in the health system are not doctors but users.[10]

The decentralising drive to shift power to the front-line of public service should extend to empowering the public. We need systems that allow people and patients to be recognised as producers and participants, not just receivers of services. Such a distributed system would have to operate close to people, dispensing continuing support, non-medical as well as medical knowledge, and be highly adaptable to people's different and emerging needs. Services would be configured around the user not the institutions into which they are forced to fit.

To make an impact, know-how and advice has to be close at hand for people to draw upon it when it's most appropriate. The nature of chronic disease and the complex causal factors which must be addressed in any preventative strategy (including social, economic and environmental factors) entail the need for services which can be continually adapted around local specificities and the life progression of the user. People will need different kinds of support as their lives change, they age and potentially develops a condition. A preventative strategy designed for a leafy suburb is unlikely to be suitable for an inner city estate.

Current approaches which are centrally controlled lack this ability to fit and flex to changing needs and conditions. This is not just a question of place and physical access. People will only feel empowered to participate in the creation or uptake of a new service if it speaks to them in a language they understand and in a style that is found to be friendly and appealing. New approaches will also have to acknowledge that people need access to a wider range of expertise than medical knowledge alone. No single institution or profession provides this mix of expertise that might include counselling, alternative therapies, sports, social and cultural activities.

Institutions process problems in a linear fashion, along a value chain. But many of the issues we are concerned with—smoking, obesity,

10 Royston et al 2004

chronic conditions—have complex, overlapping causes. Solutions need to be assembled around people and their distinctive needs rather than defined within organisational hierarchies. Services will also have to change over time to fit life patterns and to continue to adapt to the rapid pace of social change. Just as Amazon constantly adapts the service it offers making changes without disrupting service delivery, new public services will have to adapt in ways that can no longer be centrally controlled.

Distributed approaches work with the grain of what people want. Preventative approaches are designed to keep individuals outside of the health care system. Those who do need medical care do not always like going to hospitals or surgeries. They may want to be able to care for themselves more effectively in their own homes and neighbourhoods without having to turn to doctors.

What kinds of resources need to be distributed and how?

Advice and know-how
First we need to distribute the kind of health knowledge that is usually only available inside institutions. The creation of 3,000 community matrons and nurses is a step in the right direction.[11] Second, we need to build up the resources of expert patients and carers, who could become peer-to-peer providers of support. The BBC recently launched a 'neighbourhood gardener' scheme in which thousands of local gardeners will be trained as mentors for others. A similar approach should be pursued in health: expert patients and carers who can mentor others with similar problems. Third, we need to make more of distributed resources already available but which are under-utilised: public libraries and community pharmacies, for example.

Money and resources
Distributed solutions will only emerge if budgets are decentralised. As we have seen, responses are likely to cut across traditional institutional boundaries with implications for financial flows and resources. At the moment budgets are devolved to institutions for expenditure on services. Distributed solutions will require budgets to be devolved to people and communities seeking to create new services.

Resources will need to follow distributed, decentralised decision

11 NHS Improvement Plan 2004

making. Those who are already sufferers of long-term chronic conditions might get direct payments to commission the care they need, either from the formal health system or increasingly from the range of new services that are likely to emerge. The evidence of experiments in patient choice shows that this will work only if users are given support and advice from mentors and personal care assistants who help them commission their care. Those who have innovative ideas for the creation of preventative services that will take the pressure off existing curative services will also need access to development funds and resources that might turn their ideas into reality.

What is implied here builds on but goes beyond current ideas in the NHS that individuals become 'budget holders', and in public services more widely that citizens might have individual vouchers. Given that collective community based strategies will be most effective in promoting health and managing chronic diseases, financial systems will have to facilitate the aggregation of budgets. The World Bank Social Investment Funds for example distribute funds to a community which can decide locally on the services in which it wishes to invest, crossing traditional silos if necessary. In the UK, programmes such as the New Deal for Communities and the New Opportunity Funds have taken steps in this direction.

At the level of local government, recent innovations with smart card technology, including pilots in Belfast, Kent and Surrey, provide an example of a new technology that would enable the distribution of resources. A challenge for the co-creation model would be to develop ways in which collectives might both be able to debit distributed resources, but also build up credit derived from cost savings or earnings accruing from new initiatves.

Distributed solutions are likely to draw in both formal and informal resources. In other words our argument is not just about new ways of distributing existing budgets. The aggregation of activities that cross sectoral, organisational and public/private boundaries is likely to produce novel resources and new combinations of existing finance in a similar way to which new knowledge will be produced through distributive networks.[12] In some cases these new resources will come from valorising goods that were not previously recognised such as the time of users and carers, in others they will come from aggregation.

12 See Nooteboom 2001 and Zuboff and Maxmin 2003

For example a 40p school meal of low nutritional value might be improved when pupils are motivated to contribute the additional sums spent daily on snacks (estimated at three times this value).

To support such changes, health and lifestyle issues should play a more prominent role in other policy initiatives such as neighbourhood renewal and urban regeneration. Policies to get people taking more exercise depend on making public spaces safe and accessible. Policies to get people to eat more healthily depend on access to shops that sell good food.

Technology and tools

Distributed solutions will be made easier by the spread of miniaturised and low cost medical technologies for testing, diagnosis, monitoring and treatment. In the summer of 2004 the lowly pedometer became a fashion among young people, measuring how far they walk each day. In the next decade, with the spread of intelligent and interactive digital television, it's possible that telemedicine will finally come into its own. There may be huge scope for mobile telephones to carry health information. For example they could be equipped with fat calculators or bar-code scanners to establish the fat content of food.

Technology underpins new collective forms of organisation. Services such as NHS Direct have used technology to open new channels of access to traditional services. They could be redesigned to provide a platform for peer-to-peer advice. In the United States for example a pioneering initiative has established peer to peer networks among women with breast cancer, enabling sufferers to support each other with positive outcomes in terms of attitudes and well-being.[13] The BBC could play a critical role in creating these public, peer-to-peer platforms alongside existing voluntary groups.

Collaborative solutions

The market already plays a vital role in distributing health care through chemists, gyms and alternative therapies. Market based solutions will be important in addressing lifestyle issues. But a distributed strategy would fail if it relied on the market to deliver individualised and privatised solutions. We need distributed *and* shared solutions. Why?

Social support and a sense of belonging, being part of a social

13 Leiberman et al 2004. See also Comprehensive Health Enhancement Support System (CHESS), http://www.psycho-oncology.net/forum/CHESS.html

network, are a vital part of good health. People who are part of social networks are generally healthier than people who feel isolated. People who are part of a community have access to care and support from friends and neighbours. They also tend to have higher self-esteem and confidence from a sense of social belonging.

Collaboration is vital for people to share and spread ideas and know-how. Ideas propagate and grow in communities. People seeking individualised solutions will be cut off from this flow of peer-to-peer advice. Collaboratives give people greater combined weight in the system, as a voice, campaigning for improvements to services or better labelling on products.

Individualised solutions—hiring personal trainers, buying your own care—are easiest to access for the best off. They would leave many of the worst off under-served. We need community-based solutions to help the worst off and least able to maintain healthy lives. Collaborative solutions are vital to crack the most intractable problems. More affluent and better educated people are more able to change their lifestyles. That is why smoking has declined most among the best off and least among the poorest. In low income areas, collaborative buying power might become critical to allow communities to buy healthier food.

What forms of collaboration do we have in mind?

Breakthrough collaboratives
Breakthrough collaboratives have an impressive track record in the NHS: professionals jointly devise new service solutions. The same methodology could be applied to community and lifestyle issues. Public health breakthrough collaboratives might be local in scope: groups of users, professionals, from health and other services, local businesses, voluntary groups, and front line staff combining to devise new approaches to diet and exercise on housing estates, for example. They could also address specific conditions: diabetes, arthritis, asthma. These collaboratives would be a mixture of intense face-to-face interaction, shared facilities and online organisation.

Collaborative expert patients
The expert patient programme should be extended to create stronger

1

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(24 hours)

SELF assessment

What is self-assessment?

Self-Assessment gives people the choice to assess their own care needs or carry out an assessment on behalf of someone else. If it is agreed that you qualify for support, you will be able to choose from a range of support services matching your assessed needs.

This page - skip to:

What does it do?


Green Gym
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OPEN DAY
ALL WELCOME


COMING SOON
NOW ON AT
THE CENTRE
CAFE


Greenhalgh's
RICE
UTLET

Could you have diabetes?

One million people in the UK have diabetes without knowing it.

Could you be one of them?

If you have diabetes it's much better to know, so that it can be managed properly. Diabetes which is not treated can cause serious health problems including damage to your eyesight, kidneys, heart and nerves.

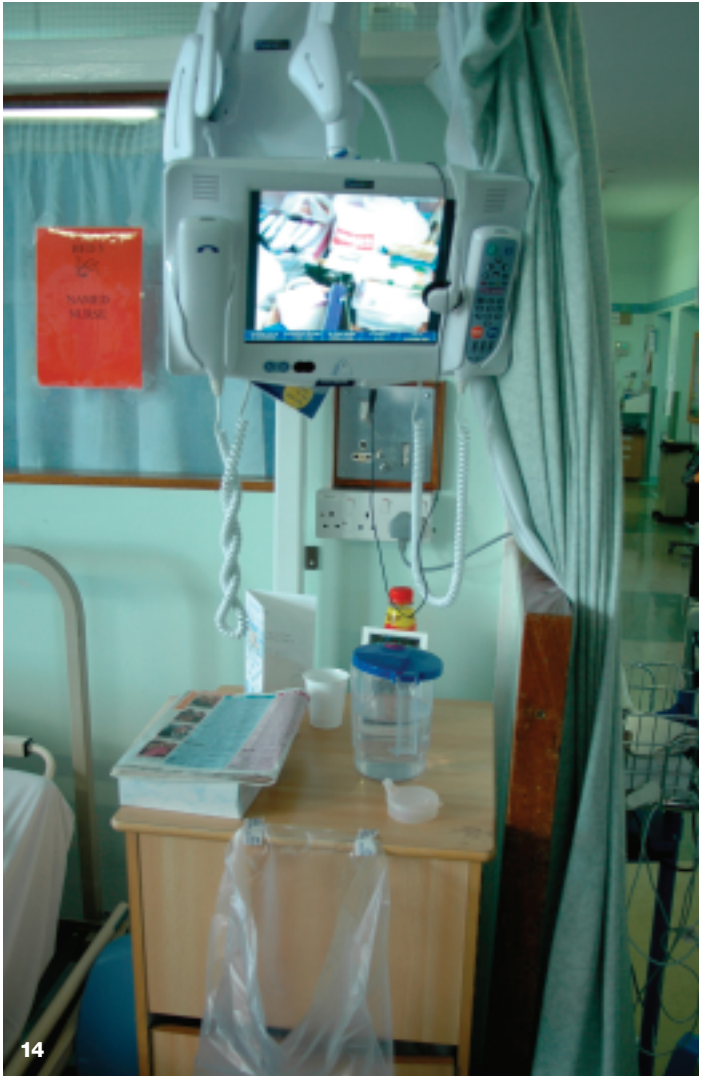
Pick up a postcard to find out more about signs and risks of diabetes

Bolton NHS
Primary Care Trust

Travel
Flu?


Prescriptions


Improving diabetes healthcare in England
Diabetes UK
Excel in Health and Fitness
active health


NAMED
NURSE

1 Kent County Council offices, Maidstone
2 Kent County Council social services online self-assessment tool
3 Bell Wood Community Primary School, Park Wood estate: talking to the head teacher and head of the local residents' association
4 Houses on Park Wood estate
5 The Green Gym, an alternative well-being initiative at Park Wood
6 Healthy Living Centre, Park Wood
7 Discussing security at Park Wood with the local police Community Support Officer
8 RED team initial analysis workshop in Kent
9 Bolton town centre
10 Bolton Primary Care Trust information campaign poster
11 Meeting with the practice nurse at Pikes Lane Centre, Bolton
12 Cohens Pharmacy, Pikes Lane Centre
13 NHS and local well-being information
14 Cardiology and diabetes ward, Bolton Hospitals Trust
15 Workshop facilitated by RED team members

peer-to-peer support groups that people could join as a complement to seeing a doctor or asking for advice from NHS Direct.

Self-help groups have been particularly effective in helping people cope with mental illness and psychiatric problems. Studies show that people who are part of self-help groups are far less likely to return to hospital. Studies of diabetics show that those involved in patient led support groups have better knowledge of their condition, higher quality of life and lower rates of depression. People who join weight-loss programmes, are far more likely to sustain their weight loss if they are part of a self-help group. Self-help groups among elderly people and their carers help reduce feelings of anxiety and depression, which often exacerbate medical conditions.

The oldest and best known collaborative self-help organisations are probably Alcoholics Anonymous and Recovery Inc, established in 1935 and 1937 respectively. The self-help movement grew rapidly in the 1970s and 1980s when lay patient groups began to develop a powerful critique of the way professionalised health care sidelined the role of families and communities in supporting people. The modern inheritors of the self-help tradition are organisations such as Braintalk, on online self-help group for neurology patients, set up in the early 1990s by two healthcare professionals, which has been used by more than 200,000 patients. One of the founders Dan Hoch explained: 'Forums like these are profoundly changing the dynamics of health care. They provide compassionate support, often face-to-face. But the 24 hour, 7 days a week nature of electronic communication is qualitatively different. It has greatly accelerated the shift away from the top-down paternalistic model of doctor-patient interaction.'

Whenever anyone visits a doctor or asks a question of NHS Direct or just trawls the Internet searching for health advice they could be redirected to a collaborative self-help group, that should be able to put them in touch with a local mentor or organiser. The National Childbirth Trust (NCT) provides an example: a source of expert information, the NCT also facilitates groups for first time parents. The primary objective is to establish communities of co-support, a secondary objective is to allow a professional midwife to share their expertise with the community.

Co-created services

Distributed and collaborative approaches will only be effective if they enable co-created services. At the heart of the approach is a new role for users who will no longer be just on the receiving end of services. Instead they will be vital to the design and delivery of services, working with professionals and front line staff to devise effective solutions.

The point is not just to deliver distributed versions of traditional services. Nor is it simply self-service: getting the users to do more of the work within a traditional service format. Users play a far larger role in helping to identify needs, propose solutions, test them out and implement them, together.[14]

Services are jointly designed by users, frontline workers and professionals through a process of dialogue that goes beyond the initial perspectives of any one party. Co-creation is not a one off event, like a referendum in which the community decides what should be done. Developing services that promote health will take more time. Nor is co-creation just a question of formal consultation in which professionals give users a chance to voice their views on a limited number of alternatives. It is a more creative and interactive process which challenges the views of all parties and seeks to combine professional and local expertise in new ways.

As a *British Medical Journal* editorial put it: 'The key to successful doctor-patient partnerships is to recognise that patients are experts too. The doctor is, or should be, well informed about diagnostic techniques, the causes of disease, prognosis, treatment options and preventive strategies, but only the patient knows about his or her experience of illness, social circumstances, habits and behaviour, attitudes to risk, values and preferences. Both types of knowledge are needed to manage illness successfully, so both parties should be prepared to share information and take decisions jointly.'[15]

People do not make lifestyle choices about their health in classically rational ways. Often they know an activity may cause long-term disease but still do nothing to change their habits. People change their lifestyles when they feel a sense of urgency; they have the confidence that they can change; they believe that changing their lifestyle will have direct benefits and they know they have the support they need to help them

14 Prahalad and Venkat 2004 provides an alternative individual view of co-creation. See also Hippel 1988 on the role of users in innovation.
15 Goodare and Lockwood 1999

through the process. That often involves conversation, dialogue and debate. Making good on a decision to give up smoking, is a far more complex and drawn out process than choosing which washing machine to buy. Co-creation should provide people with the support they need to follow through on decisions.[16]

Engaging in this way encourages risk sharing and an informed discussion about trade offs and priorities. Users are no longer left infantilised and demanding ever more services, rather they are informed and emotionally engaged, allowing them to participate in critical decision making processes.

The role of professionals and front line workers will similarly undergo transformation. Professionals will act as facilitators, mentors, and sources of knowledge needed to help users devise and manage their own solutions. To tackle some health issues, for example, diet and exercise, a broader professional alliance, including food and agriculture, culture and transport, housing and education as well as leisure and sports, is required.

Shropshire's home help services and Kent's recuperative care services depend on frontline staff working intensively with users to support them to regain their independence.[17] The Evercare programme developed in the US and currently being piloted in the UK aims to improve the quality of life for vulnerable older people. Their focus is on helping older people maintain their independence and improve their well-being. Early reports suggest that much can be achieved by reallocating existing resources to new purposes and developing new ways of working for healthcare professionals.[18]

Co-creation is vital to win the engagement that Wanless calls for. Co-creation allows people to tailor solutions to their local and distinctive needs. Critically a co-creation approach sees those who participated in the design of the service committed to its implementation. Interaction and dialogue cannot be just talk, although some users will find it cathartic just to have their views heard. People who are consulted about services feel let down when no action is taken. Co-creation should commit producer and user to a joint plan of action.

16 Zuboff and Maxmin 2003
17 Leadbeater 2003. See also http://www.shropshireonline.gov.uk/olderpeople.nfs/open/33A9D043F9686B3C80256ED20031CFD8 and http://www.kent.gov.uk/ss/otbureau/recuperative.html
18 http://www.natpact.nhs.uk/uploads/Advancing%20the%20National%20Health%20Service%20Interim%202-04%final.doc

5 Communities of Co-creation: New Organisational Forms

We need distributed, collaborative and co-created solutions. To make that combination possible, at scale, we need new organisational solutions. The decentralised, networked responses we envisage will not emerge on their own accord. They will only come about through concerted reforms to create more distributed capacity, to provide spaces in which people can collaborate and devise co-created solutions. That organisation cannot be delivered top down, in the shape of a traditional institution. We need a minimal level of external, professional design to allow bottom-up initiative from within society.

We call these new organisational models 'communities of co-creation'. They will harness distributed resources, at scale, creating a platform on which the least confident and poorest can take charge of their health. Communities of the kind we envisage are well developed in software and over the last decade the principles behind this highly collaborative approach have increasingly been applied to other fields including professional associations, knowledge networks and manufacturing.[19] These open source style communities offer a promising organisational model for 'communities of co-creation'.

Mass, peer-to-peer organisations are large scale, highly distributed systems which combine many players to carry out complex tasks—developing software, trading goods and services—without requiring burdensome, top-down hierarchical organisation. Examples include:

> eBay, the peer-to-peer trading system. eBay the company employs about 25,000 people but more than 120 million people are registered users of the tools and platform that eBay makes available to buy and sell virtually any kind of goods.
>
> Linux, the open software programme is the work of a distributed collective of perhaps 120,000 registered developers. A small core

19 Lessig 2001

of about 1,000 make most of the significant contributions. Anyone can pick up and use Linux, fiddle with the code and adapt it.

Computer games such as The Sims rely on users to contribute much of the content, making that available to other users.

Astronomy has been transformed by the growth of collaborative networks. There are some 10,000 professional astronomers in the world but hundreds of thousands of dedicated amateurs who now collaborate across the Internet. Increasingly astronomy is a science in which a small body of professionals will work in alliance with a vast army of dedicated amateurs.

The Grameen Bank, one of the largest micro-finance lenders in the world, makes small loans to millions of poor Bangladeshi farmers. It uses 'barefoot' bankers and lending committees in villages which share responsibility for making loans.

These communities of co-creation are more than loose networks: they have a structure for making decisions and evaluating information. They can achieve tasks as complex as any large organisation: Linux produces the main competitor to Microsoft, an operating system that runs computers for governments and large companies all over the world.

They have been enabled by the Internet and digital communications, which allow ideas to be shared. Communities of co-creation are social innovations as much as technological: they make possible co-operative innovation on a massive scale, systematically combining the contributions of many people, who are simultaneously users and producers.[20] Communities of co-creation work when they have these characteristics:

The community has to form around something. It does not spring out of thin air. In Linux this was Linus Torvalds' original kernel for the programme. In health, the kernel of communities—advice, support sessions, self-diagnostic tools would probably be provided by lead-users working with professionals.

Members usually bring something to join the community. That might simply be a problem to solve or a question to ask. It might be an idea or an offer of support.

20 For more on the nature of open source organisations see Weber 2004 and Feldman et al 2004

Contributions are judged and accredited according to an open, peer based system. eBay does this with a very simple rating system, in which buyers rate the performance of sellers, who can then build up a reputation within the system. This is how the community jointly filters good information from bad, a function much needed in health where the Internet overflows with information.

They solve problems to provide better software, buy and sell goods more effectively or download songs. They are primarily problem-solving communities, not ethical and altruistic.

People learn through their participation. They may also acquire a sense of status and recognition for their contributions.

They decentralise initiative by distributing easy-to-use tools. This is a matter of necessity as much as principle. The founders of eBay set up bulletin boards on which users could answer one another's questions—something that became a central feature of the community—because the fledgling company did not have the resources to answer them centrally.

They are designed to evolve. People can add to them, building on the contributions of others. There is no designer at the centre with a complete view of where the community should go. This approach is particularly well suited to health conditions where medical knowledge is still evolving.

Ideas can be proposed, tested and judged quickly, according to commonly accepted yardsticks. It is more difficult to do this in systems in which someone's life is at stake or in which it takes a long time to thoroughly test out a new idea. Both these qualifications apply to health.

In traditional organisations labour is directed to tasks by management. In these communities people are attracted to tasks that interest them. It is a distribution of labour, bottom up, not a division of labour top down.

They rely on open forms of leadership. Open leaders create the framework in which other people can make decisions by setting out simple values and rules, that people can turn to when they

are solving their own, localised problems.

Ownership is blurred. The founders can never completely own the community. eBay the company, is virtually nothing without eBay the community. The NHS and its professionals cannot own the communities we propose.

The combined know-how, labour and engagement of patients, carers and people concerned to live healthily is a significant untapped health resource. If this expertise can be mobilised systematically over the next decade it will have a huge impact on health outcomes. This will require organisations quite unlike the institutions we currently rely upon, that agglomerate professional knowledge. We need organisations that allow all kinds of people to participate, sharing ideas and advice, support and encouragement.

We believe these communities of co-creation models can be applied to health. As we look at testing these approaches in practice a series of questions are raised. How would people be motivated to join in? This question is particularly pertinent to services that might be designed to promote good health. What resources do people bring to the community? To join Linux one has to have some skills in software. Will these communities be as effective when people need more intimate, emotional and social support? Thoughtful design will be needed to address these issues.

6
The Role of Design: Tools for Co-creation

Developing co-created services will necessarily be dependent on a set of key processes that support and enable the distribution of resources and knowledge, collaborative approaches and new interfaces between users and professionals across disciplines.

Designers turn radical innovation into practical reality on a daily basis, be that in the creation of new products and environments, or the development of services and experiences. Good design makes things and services useful, useable and desirable. Good design process focuses on the inter-relationship between users, workers, professionals and services—the challenge for effective co-creation.

Working across disciplines and institutions

Design is a process that makes connections. The design process has the proven ability to forge connections between people and organisations, unlock solutions and address change.

In the words of John Thackara: 'In an economic world dealing in knowledge, the secret of success is the re-combination of different types of expertise in a productive manner. This new kind of design sets out to increase the flow of information within and between people, organisations and communities. A new way to think about design is as a process… that stimulates continuous innovation among groups of people within continuously changing contexts'.[21]

Design then is a critical process that facilitates the combination of knowledge and expertise that will underpin the new co-created services. It draws in a range of disciplinary perspectives that will include not only designers, but policy perspectives and professional expertise. This inter-disciplinarity in turn facilitates an approach that can cut across traditional institutional boundaries and hierarchies. Such an approach will be critical to developing new co-created services which are unlikely to be bound by any one of the traditional service divisions.

21 Taken from the Introduction of John Thackara's new book *In the Bubble: Designing for a Complex World*, MIT, forthcoming

The user process

The design process is a set of techniques and approaches that puts users at its heart, works from their perspectives, engaging with articulated knowledge, latent perceptions and emotional responses. This set of techniques provides a language for dialogue that will be central to the co-creation approach. Critically the user process neither privileges the power of the professional, nor does it necessarily take at face value the statements of the user. As we have discussed, this is a process that goes beyond populist participation or the relatively shallow techniques used in consultation. The facilitator deliberately looks for anomalies and contradictions as well as patterns and averages.

Ideas change, are modified or discarded within the user research process. This movement of ideas reveals important insights into the ways in which participants prioritise, how they analyse and why they trade one idea off against another. The ability to look beyond received opinions and to articulate latent needs and emotions is of particular importance in the health field where, as we have seen, an understanding of attitudes and motivations will determine the success of co-created services. Understanding these issues will ensure that the services delivered fit seamlessly with real people's lifestyles and desires and are accessible to all.

Tools to visualise complex structures and systems from different perspectives enable the designer to present issues from different viewpoints. They facilitate dialogue between participants who do not share a common language. Visual techniques also encourage participants to plan and to act. New ideas and solutions can be made tangible thus facilitating further dialogue, fostering innovation and reducing risk. Experience shows that participants feel 'signed up' to the solutions that are co-created, ensuring that innovation is brought to life.

Usable interfaces

Design is a practical tool. It helps to make things more visible, legible, coherent and easy to navigate. New co-created service models will require new types of interaction to take place between people, technology and infrastructure. Good design will ensure 'user friendly' interfaces that better support new services.

Platforms, tools and motivators

Distributed, collaborative services will involve the need for new tools and platforms that enable the sharing of knowledge and resources and the continual adaptation of services. It may not be possible to fully design or formalise co-created services. Space must be left for the users of the service to continue to innovate, and for the service itself to adapt and evolve. We can however design the conditions for these new services to evolve.

Open systems need a common operating platform (a place, a piece of software, a set of rules) and tools that allow and encourage people to contribute. Many of the unanswered questions around the potential of a co-creation approach concern the way in which both users and professionals will be encouraged, motivated and enabled to engage in meaningful ways. Motivations that drive people to participate may include financial gain, learning and personal development, social interaction and protest. A design approach can offer the practical creation or activation of each of these elements.

As we have moved into a service economy, design is increasingly employed to raise the value of intangible commodities such as services, brands and experiences, all of which require the participation of the consumer. This involves tapping into people's perceptions, expectations, latent desires and motivations. It involves designing services and experiences in a way that both delights, appealing to people's emotions and desires, and recognises the value in participating. Some of these values are themselves intangible—better health in the long term for example is a particularly intangible reward. Much of design's role in developing co-created services is to increase that sense of value, creatively recombining motivations to create compelling services.

At the same time, the co-creation approach raises challenges for designers and the design community. Designers have continually had to adapt and expand their skills as public services have developed, moving from product design into brand, packaging and communications, and more recently, using their skills as service and systems designers to support personalised services. Co-creating services however presents radical new demands which in some ways challenge the role of the profession itself. Designers, like other professionals, will have to learn to work in new ways and at times to cede power within a system in which, to some extent, everyone is a designer.

7
The Prototype Sites: Co-creating in Practice

The approach outlined in this paper is being tested in practice with partners in Kent and Bolton. In Kent we are looking at co-creating services for successful ageing, in Bolton we are looking at co-creating services for chronic disease management, using diabetes as a case study.

A rapid six month project will see the interdisciplinary RED team including designers, health experts, an economist, anthropologist and policy makers working in partnership with professionals, front line workers and residents in Kent and Bolton. A user focused design process will provide the framework for: testing in practice the ideas outlined in this paper; creating practical prototype solutions that demonstrate new organisational models and scenarios for future co-created services; generating early policy recommendations that would support the formation of these new models and modes of development for the NHS, the Department of Health and the government.

As we have stated in this paper, our ideas build upon an important number of initiatives that already contain the seeds of a co-creation approach. Similarly, in Kent and Bolton we will be building upon a number of highly innovative strategies developed by professionals within the health service and local government. We believe however that there is a particular need to develop further practical ideas that support alternative approaches to prevention; the user focus within co-creation and the means of financing new services and activities.

Kent: promoting successful ageing

Kent is pioneering a new approach to public service agreements which moves beyond the provision of excellent public services to an ambition which seeks to improve the very experience of working, learning and relaxing. Aware that attempts by government (local and central) to persuade individuals to curtail damaging habits such as smoking and cultivate positive ones such as exercise are at best futile

and at worst unpopular, Kent is keen to explore a new approach to promoting well-being.

The problem posed by Kent to the Design Council's RED unit is how to incentivise the 50 to 70 age group to keep healthy and active in order to reduce the likelihood of age related illness (such as fractures, osteoporosis, Alzheimers, diabetes). Kent's question is what would motivate people to want to enjoy more active lives. A closely associated issue for Kent is the challenge of measuring success in terms of health as well as the reduction in disease.

The RED project will focus on Park Wood, a deprived community in the Maidstone area, where the average household income is half that of Maidstone in general, 17 per cent of the working age population is on income support and one in five of the population has a limiting long-term illness, with 8 per cent providing unpaid care to a relative.

This local focus will ensure that individual motivations can be understood and tangible outcomes developed. Focusing on a place will enable us to build on the existing positive initiatives and relationships between residents and front line workers while questioning some of the current assumptions behind service provision. Initial interviews and observations with residents and key workers on the estate for example reveal that a co-created service to promote activity and thus successful ageing would have to start by addressing issues of security on the estate and the relationships between young and old as opposed to focusing solely on an ageing population.

The intention is not to develop a specific community project but to extrapolate lessons that can be used more broadly in Kent for the co-creation of well-being services. Success will entail designing effective interfaces between locally developed solutions and the work of the Primary Care Trust and Social Services. These two institutions are together pioneering new platforms such as the proposed social security smart card and on line assessment tools, the healthy living centre and funding community workers. The means of financing new services will be considered: technical achievements have the clear potential for reducing costs and we will ask how these might be best achieved and how resources might be re-invested.

Bolton: managing diabetes

In Bolton an estimated 10,000 residents suffer from diabetes (almost one individual in every ten households). This absorbs 5 percent of NHS resources locally, and 10 per cent of hospital patient resources, a pattern that is similar to that nationally, exemplifying the challenges of chronic disease management.

In response, Bolton has developed an exemplary strategy. Diabetes type 2 (which makes up 85% of the cases) is seen in the first instance as preventable and, if it occurs, as containable through adequate self medication and treatment regimes. Exceptionally, a leading group of professionals from different organisations and disciplines have argued for a radical re-organisation of a service, over and above the particular interests of their own institutions. There is a near unanimous view that the service needs to be re-structured around the patient and to this end significant steps have been taken with attempts to establish user support groups and the opening of a diabetes centre, away from the hospital.

Progress to date has been largely inspired by the professional managers and clinicians rather than diabetics themselves. A medical model of engaging with diabetics and residents more generally has found itself to be limited. The interface between patients, professionals and workers in the diabetic centre has proven to be a particularly intractable problem. In the words of one clinician, improving this interface 'would make a good service fabulous', but a different cultural approach is needed.

This is the problematic on which the RED project is centred. The co-creation approach argues that service re-organisation will need to be bottom up as well as top down and will involve professionals and workers engaging in new ways with their patients. Initial interviews and observations with front line staff and patients have revealed the need to further distribute services and resources within the community. And they have emphasised the difficulties of motivating engagement and behaviour change on the part of the people with diabetes, many of whom prefer to ignore the implications and the required actions that make current life difficult and the acknowledgement of being a diabetic frightening.

The project will look at the ways in which the interface between people with diabetes and a range of required services can be made seamless and at ways in which diabetics might co-support each other. A co-created service will entail both participation and change on the part of the diabetics themselves and the professionals currently engaged in delivering services—many of whom look forward to a time when they can spend less time on acute cases and more on bringing their knowledge to bear on the design of support services and training.

While this project will focus on the well-being of those who have already been diagnosed as diabetics, the preventative principle will continue to inform the development of the project. The secondary prevention of complications depends critically on the person with diabetes, their lifestyle and their monitoring and self medication, delivering both therapeutic and economic benefits. It will also have continuing implications for the organisation of the service itself and for continuing bottlenecks. In Bolton for example there is a two year waiting list for orthopaedic shoe fittings (cost £100) which can save the need for amputations (cost between £30,000 and £40,000). Such bottlenecks are far from unique to Bolton or to diabetes management and reinforce the need to maintain prevention as a founding principle in the approach to co-creating services.

8
The Future of Public Services

Making current delivery systems more efficient will not tackle the big issues of lifestyle and chronic conditions. We need systemic and radical innovation. The 'communities of co-creation' we are arguing for will draw upon existing resources, in hospitals, households and communities. But they will mark a radical break with 20th century modes of organisation.

In the 20th century, public goods were produced by professionals working in dedicated, hierarchical organisations, delivering packets of service to waiting, deferential users: doctors made you better, teachers provided education, police caught criminals.

In the 21st century, public goods and services will be created interactively, through partnerships between professionals and users, and by user collaboratives. These alliances, partnerships and communities will co-create new services.

In the 20th century, big gains came from formalising the provision of professional knowledge through systems of training and provision and institutionalised, mass service provision.

In the 21st century, the big gains will come from professionals mobilising a far larger body of lay knowledge among users. Organisations that can mobilise the intelligence, investment and imagination of their users will reap huge gains in cost, productivity, flexibility and innovation.

Current models of organisation mean that better services can only be delivered by employing more public service professionals: more education means more teachers; safer streets mean more police.

Tapping the potential for co-creation between professionals and users will be central to the quality of life in the UK and the future of public services. Co-creation is not just about giving users a larger say in shaping the delivery of existing services. Co-creation is not just

co-production, in which users self service by doing some of the work previously done by support staff and professionals. Co-creation should be the foundation for services, configured and organised in new ways, in which users are participants in the design, creation and delivery of services, investing their time, effort and labour into the process, sharing some of the risks and responsibilities for outcomes with the professionals.

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