

RED **REPORT 01** **Open Health**

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Contents

Foreword page 03

Propositions

I The NHS reforms: the search for post-modernisation page 04

II Ways of caring page 08

III A design approach page 10

Prototypes

IV Diabetes in Bolton page 12

V Activity in Kent page 18

VI Design for engagement page 26

Systems

VII Open Health page 29

VIII The distributive principle page 32

IX Co-creation revisited page 36

X Deep support page 39

XI New forms of organisation page 41

XII Designing for Open Health page 44

Transition

XIII The climate of health page 49

XIV Open transitions page 56

Bibliography page 58

Notes page 62

The full Design Notes can be downloaded as a separate document at www.designcouncil.org.uk/red.

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Foreword

This report follows on from the RED Paper 01 Health: Co-creating Services and presents the findings of practical work undertaken over the 9 months from December 2004. The report remains work in progress and we welcome comment. Over the coming months we will be looking at taking this work to a different scale working in partnership with other health and non-health organisations. Regular updates on our progress will be posted on our blog – www.designcouncil.org.uk/red

About RED

RED is a 'do tank' that develops innovative thinking and practice on social and economic problems through design innovation.

RED challenges accepted thinking. We design new public services, systems, and products that address social and economic problems. These problems are increasingly complex and yet traditional public services are ill-equipped to address them. Design innovation is required to re-connect public services to people and the everyday problems that they face.

RED harnesses the creativity of users and front line workers to co-create new public services that better address these complex problems. We place the user at the centre of the design process and reduce the risk of failure by rapidly proto-typing our ideas to generate user feedback. This also enables us to transfer ideas into action quickly.

RED is a small inter-disciplinary team with a track record in design innovation. We have delivered £14m worth of successful projects in the last 5 years. We have a network of world-leading experts who work with us on different projects.

In the last 5 years RED has used design innovation to prevent ill-health, manage chronic illnesses, reduce energy use at home, strengthen citizenship, reduce re-offending by prisoners, and improve learning at school. We have worked with government departments and agencies, Local Authorities, frontline providers, the voluntary sector and private companies.

The NHS reforms: the search for post-modernisation

Healthcare is in the midst of an historic transition. Shaped as it was by the 19th century problems of contagious and acute disease, and institutionalised as a National Health Service in the organisational model of the mass production era, the structures now have to cope with a new epidemic of chronic disease.

The latest official Health Survey reports that 45 per cent of the adult population of the UK has one or more long-standing illness. For those of 75 or over the figure is three-quarters. Circulatory diseases and cancer alone, which made up 19 per cent of deaths in 1900, now cause 63 per cent of all mortality. We may be living longer, but the chronic diseases we suffer have been rising insistently.

One result is an increasing pressure on GPs and hospitals, which themselves exhibit many of the symptoms of a system under stress: long hours, high drop-out rates, and compressed consultation times.¹ Another is the pressure on finance. In 1997 the Government's health spending was £33 billion. By 2003/04 it had doubled to £67 billion. Derek Wanless in his 2004 report on the future financing of the NHS, estimated that without significant changes, health spending in real terms would have to double again within 15 years to keep pace with demand, with health spending rising from 7.7% to 11 per cent of GDP within a decade.

Much of the political debate on health has been around these symptoms: the length of queues, the responsiveness of the service and the level of spending. But these are symptoms, and will not be altered by changes of ownership or the introduction of choice as to how and by whom these symptoms will be treated. The challenge to healthcare is more profound.

The NHS as a mass service

The central question is the model of industrial production that is appropriate for a modern healthcare system. The NHS system that developed after 1948 was something of a hybrid industrial process. On the one hand it was similar to branches of engineering where a part (in this case a passive patient) was worked on in successive stages by highly skilled craft workers (medical practitioners).

On the other hand it had many features of the mass production model that was transforming manufacturing industry. It was conceived as a universal service, serving an undifferentiated mass population. The bulk of resources was concentrated on centralised hospitals that dealt with acute cases according to standard procedures and protocols. Unlike a traditional car factory, there were multiple production lines, and it was the task of diagnosis at the level of primary and second care to determine which of the lines was appropriate for an individual patient. Innovation in the form of a change of treatment (either through the nature of invasive surgery or the administration of drugs or other regime) was largely undertaken after extensive and costly research to establish the safety and latterly the cost effectiveness of the proposed innovation.

The key point is that it was a linear system, based on the flow of the patient through successive stages of diagnosis and treatment. There might be feedback loops of re-assessment and the adjustment of treatment, but the prevailing concept was the movement of the patient along a care pathway.

The main changes that took place in the second half of the twentieth century were the development of specialist medical knowledge, and of diagnostic, pharmaceutical, and operational technologies within this model of health care. For many conditions this has led to major improvements in treatment and outcome, for example in hip replacements, or the treatment of cardio-vascular diseases and some cancers.

The growth of chronic disease

But for others the model is less effective. One is mental illness, where hospitals traditionally played the role of containment rather than cure. In 2000, ten million people of working age were assessed as having a neurotic disorder, but fewer than a quarter were receiving treatment.² Another is long-term care, which by the 1980s accounted for 40 per cent of hospital beds. There are many diseases for which there is no ready cure (such as arthritis, Alzheimer's and many cancers) or for which the treatment required is continuous rather than episodic. These are all instances of chronic diseases which by the end of the century accounted for 80 per cent of NHS spending.

The principal problems posed by chronic diseases are three-fold. First an increasing proportion of them are clearly the result of individual, social and environmental factors, many of which are in principle preventable. The mass production model had notable success in the prevention of contagious diseases through centralised action and mass treatments like immunisation. But its techniques are much blunter in relation to today's chronic conditions, the 'l' diseases that are connected to how people live their lives. Influencing life styles to reduce ill health - often in the face of deep attachments to the causes of ill health (smoking, drinking, diet or inactivity) - calls for a different approach.

Second, once chronic disease has set in, many long-term treatments depend as much if not more on the actions of the patient as on those of the medical staff. In these cases the model of treatment of the patient as object is inappropriate for a regime of self-care. Patients can no longer be treated as the passive recipients of recommended standardised routines, but have to have a regime of support tailored to their specific characters and needs. Those suffering chronic conditions, and those close to them, have to be seen as producers as much as consumers of healthcare. They are the subject as well as the object of treatment, and require a different relationship with medical professionals.

Third, the growth in chronic conditions and the limitations of the current model of healthcare in preventing and treating them, leads in the end, as conditions deteriorate, to a growing demand for acute care. The acute care of chronic conditions is one of the primary factors in the pressure on NHS resources. It leads to the continued dominance of hospital spending in the NHS budget (60 per cent in 2003), and the crowding out of long-term investment in prevention (4 per cent in 2002). The immediate demands cannot be ignored. Heart attacks have to be treated. But it is as though the system is locked in a negative vortex, where because of its incapacity to tackle prevention, it is forced to concentrate its resources on high cost treatments of acute conditions which might have been avoided in the first place.

A post-Fordist health service

There have been two main policy responses. The first and most controversial kind are those that relate to what economists refer to as the sphere of circulation - with how markets work, how resources are allocated, how this affects the distribution of services and what role is played by consumers. The debates around this are reminiscent of those over market socialism in the more liberal East European states in the 1970s and 1980s, where the economy had similarities with the NHS, centrally planned and managed, publicly funded, with many services free at the point of delivery.

The UK's current health service reforms can be seen as a kind of perestroika, which, while retaining a publicly funded service free at the point of delivery, introduce patient choice, greater contestability between providers, and most profoundly, radical financial reforms that allow money to follow the patient.

The goal of the reforms is to open up the system of provision, and decentralise the control of funds if not to patients then to primary care trusts and general practices, with the centre's role redefined as providing synthesis in the form of a unified information system, treatment protocols, and an elaborate regime of performance auditing. This, it is hoped, will diversify access and treatment, and re-orient the service to the expressed needs of the patient. Taken together the reforms signal the most far reaching changes in the organisation of the NHS since it was founded.

Their primary logic has been to change the service rather than counter the escalating costs of healthcare. The cost and productivity issue has been addressed by a second less-publicised strategy of introducing into health the kind of changes that have taken place in manufacturing since the 1980s. In part this is a matter of improving the use of ICT within the NHS, and of common types of commercial 'rationalisation' (paying increased attention to the cost effectiveness of services provided, for example). There has been an increased emphasis on specialisation, and, like the stripping out of non core activities from manufacturers, a decentralisation of many forms of diagnosis and treatment, from consultants to specialist GPs, from GPs to practice nurses, from general hospitals to specialist treatment centres, and from surgeries to pharmacies.³ Most strikingly, there has been an ambitious project of applying Japanese manufacturing principles of just in time processing to the flow processes of hospital care.⁴

So just as Taylorism and Scientific Management, first introduced in the steel industry in the late 19th century, shaped the organisation of public services in the first half of the 20th century, so Toyotism is informing the current re-organisation of British healthcare.⁵ Set alongside the quasi-market reforms, the emerging model is one of a more diverse and specialised structure of provision, with a flexibility that permits a rapid response to the changes and particularities of user demand.

The model of mass production is replaced by one of 'mass customisation', a personalised NHS which offers 'flexible access to services shaped around individual needs and preferences rather than an expectation that people will fit the system'.⁶ It is as if Benetton had taken over the NHS.

Of course the NHS is not a manufacturing industry. It provides maintenance services. It is labour intensive, a quasi-monopolist and is still funded by taxation not markets. Its very size means that many of these reforms are of daunting complexity - notably those involving new systems of accounting and finance and the introduction of a single electronic information system. The introduction of quasi-markets and competition into a service whose driving ethic is need may well have unintended consequences. Nevertheless the reforms are driven by an assumption that in the long run the NHS can be radically improved by the adoption of innovations from modern commercial and industrial systems.

Yet these reforms in many ways by-pass the main problem. Viewed through the lens of industrial production, the central issue for the health service is that its processes, specialisms and organisation are geared to the volume processing of passive patients, when what is required is a system that can engage with the way people live and (in the case of those with a chronic disease) manage their own treatment. There has been a growing mismatch between the kind of preventative help that is needed and that which the NHS can economically supply. The industrial model of production, however flexible, and however customised to its users, is not appropriate for the principal task in hand.

Public health and self-care

This is now widely recognised. So that alongside these two main policy responses has run a third, less visible, more tentative one, one which directly addresses the core problems of chronic disease. The issues of prevention and self-care play a central part in Derek Wanless's review of the future of healthcare for the Treasury. He refers to it as the full engagement of people in the maintenance of their health. It was the subject of his third major report published in 2004, and is the pivotal strategy for limiting the growth of health service spending over the next 20 years. It offers the prospect of a shift in the NHS from being what he terms a 'National Sickness Service' to one that promotes good health and the quality of life.⁷

Wanless concluded that the fundamental challenge is not on the goal or the policies. There has been widespread agreement on them both. The issue is implementation. In the past there has been too little funding. The evidence base is weak. The multiple stakeholders have not been fully engaged. Many strategies have been proposed but not fully followed through.

The Government has immediately responded to Wanless's argument. Within a year it has made chronic care management and ill-health prevention two of the four principal future objectives for the NHS.⁸ It has produced strategies for each and there are now a series of public health delivery plans. These are all reflections of the fact that, whatever the public's response, the Government is 'fully engaged' with the problems of chronic disease. It is the most concerted attempt to deal with the issue since the establishment of the NHS.

But how? The central problem for government, and indeed for any industry based approach - is that it is difficult to apply a 'delivery' model to issues which require changes in personal behaviour. Governments can change regulations and taxes. They can provide facilities. They can conduct campaigns using conventional advertising channels, and marshalling the full apparatus of the state, its departments, agencies, municipalities, and the great network of the NHS itself. They can in this way establish new public norms and deliver the 'how to' and 'where to' information of the national instruction book. But these cannot 'deliver' changes in behaviour as if they were outputs from a production line. Rather they can create a climate in which such changes are possible. For this a new model is required.

This has been the focus for RED's project work. Through our collaboration with our partners in Bolton and Kent, we have been developing a new potential model. This report discusses the context and results of our practice.

Ways of caring

In our first RED paper *Health: Co-creating services* we set out the first sketch of an alternative.⁹ We argued that for new systems of prevention and chronic disease care the starting point should not be existing institutions, but rather individuals and their multiple communities. It pointed out that 80-90 per cent of health incidents are dealt with at home; and that changes in lifestyle depend ultimately on the decisions and actions of individuals, as does the management of chronic disease.

The informal economy of family support, of self-help groups, and social networks, as well as multiple features of the formal economy - from chemist shops, to voluntary bodies, alternative therapists, and the pervasive world of commercial marketing and consumerism - all took the field of action way beyond that covered by the NHS as formally constituted.

As suggested above, the Government and the NHS can have a substantial impact on these various fields - indeed they recognise the need to start from the individual in their first two principles of action for preventative health - informed choices and personalisation. But we argued that a new system had to include individuals in its design, to be developed from the bottom up as well as from the top down, if it was to achieve the goals of health and equity to which the Government aspires.

The RED Paper sketched out four features of a new model. It should be:

Distributed. Know-how, tools, advice and finance needed to be distributed out of institutions into communities and households to allow user-centred solutions to be assembled collectively and locally. In economic terms, each package of solutions would not only be particular and personalised - just as the contents of each supermarket trolley are a personally assembled package - but would comprise locally available and convenient resources. This was an allocational proposition about moving resources (information, advice, finance, technology and tools) into the hands of citizens/users as producers of their own well-being. It was also a geographical one of dispersing those resources spatially.

Collaborative. There are great benefits from maximising the scope for collaboration - through self-help groups for example, such as Alcoholics Anonymous, or the National Childbirth Trust, or through collaborative sessions with professionals, peer-to-peer mentoring, or on line forums. These benefits are both those of sharing information, experience and advice, and of being part of social networks that are so important for good health.

Co-created. Users, as producers, should be central to the design, production and development of services. This is not just a matter of the service package itself, but of many elements of the package and what is most appropriate. The concept suggests a creative and interactive process between users and professionals around the needs of the user.

Peer-based communities of co-creation. The distributed networks of collaborators would be organised not through a top-down hierarchical structure, but through light shells that set down rules and ways of operating that allow free peer-to-peer relations. The models evoked were from software (Linux and the free software movement), e-Bay, computer games, astronomy networks linking amateurs and professionals, and the Grameen micro-finance bank in Bangladesh. Each of these is a problem solving network, whose systems develop through the sharing and filtering of distributed knowledge.

We have called these propositions. They are ideas stimulated by many recent initiatives - open source systems, breakthrough collaboratives, peer-to-peer groups, social service and educational innovations, games like Lego Mindstorms and The Sims. Many depend on the person to person connectivity made possible by new electronic technology, and exemplify the scope created by the digital revolution for the development of distributed systems.

Open welfare

We see this as part of a wider movement towards open welfare, in which the traditional distinction between producer and consumer - or in the welfare field between the public service and the client or patient - is transformed into networks of self-acting citizens, with flexible degrees of involvement, supported in a range of ways by professionals. In other words, the user becomes a producer, and as such needs skills, tools, information, means of communication, and technical support.

Open systems of this sort are most suited to areas of complexity, where it is difficult for a centralised organisation to gather and process sufficient information to permit it to manage (and motivate) dispersed and highly differentiated activities, such as the preparation of food or the planning of journeys. Open systems hollow out and distribute complexity, and by increasing the density of communications between all parts of the system, they expand the capacity to generate ideas and information far beyond that of closed organisations. Information circulates freely through knowledge networks and accessible databases (as in the human genome mapping project), governed by relations of reciprocity rather than market exchange. The networks provide a new way of mobilising large populations of knowledge and activity.

In order to function they do not need hierarchical organisation, but rather platforms for activity and the circulation of information. They may need tools and some agreed protocols of operation. And there needs to be some means for financing any costs involved in the maintenance of the platform and the tools. The principle resources of knowledge sharing systems are the surplus time of participants who earn their living elsewhere.

Open systems are less relevant for activities which depend on highly specialised knowledge and standardised procedures, such as flying an aeroplane or operating a power station. But for any activity where the active engagement of the citizen is required such as education, or transport, or public order, open systems make possible radically different ways of meeting needs to those delivered by the traditional services of closed welfare systems.

Public health as it relates to the way individuals live, and the management of chronic disease are both areas where open welfare approaches are particularly relevant. But the ideas need to be developed and tested out in practise to see how far they can be of use in healthcare, and what is necessary to allow them to flourish.

A design approach

In exploring these propositions we were also testing out the applicability of design to public services and to the ideas of co-creation and open welfare. Design has developed as a profession over the past 150 years primarily in relation to the design of products, and more recently to the design of services. Just as the public sector has invested little in marketing (its advertising budget is 1 per cent of that of the private sector) so it has invested little in design. In health in particular the financial priority has always been to meet immediate medical needs rather than invest in what are seen as commercial practices such as marketing and design. In services geared to need rather than the market, is there then a place for design? Can the methods used for designing the iPod or Heathrow Terminal 5 be of value to the health service?

There has been some work recently on using the techniques of service design within hospitals - from redesigning signage to improving the methods of intensive care. Our interest is in the potential value of applying design to issues of transforming systems of care, notably those relating to chronic disease, and to health-related changes in lifestyle.

There are five features of design that made this a promising proposition.¹⁰ First, it is user focused. It starts by intense observation of the user in action - how an object is used or a service experienced. It looks at activities through the eyes of the user, whether making a cup of tea or going on a journey. It is concerned with the practical details of daily life, of why some things are chosen not others, with desire as much as utility. This lies at the heart of its success in the world of commodities. It could have a similar impact in a user-centred transformation of public services.

Second, it starts not from existing products but from desired outcomes. It stands back from problems as well as proposed solutions, with a view to reformulating them. For example, First Direct started out from an idea of improving banking services for their regular branch customers, and finished as a service geared to those who didn't visit their branches. In other words, design, like art, is impatient of the conventional. It applies the creativity of the avant garde to the redesign of the material world.

Third, it is a profession that unites conception and execution, constantly iterating between the two. It specialises in making rapid prototypes, to see how things work in practice, revising its concepts on the way. It describes this as a means of getting failure in early, which is another way of saying that it reduces risk. The prototypes may be objects or experiences. But they could equally well be policy instruments. These are not pilots - which involve more resources and time. Rather they are rapid mock-ups that allow the designer to test out reactions to a tangible object or service.

The integration of conception and execution provides a double benefit. On the one hand designers are committed to practical outcomes, to finding solutions that work in practice. On the other, the conception and strategies that arise from the process are informed by and rooted in practice. Thus all those involved are committed to the practical outcomes.

Fourth, design seeks to make ideas visible and solutions tangible and the tangibility of its practices - not just through prototypes, but in its use of multi-media tools - photographs, videos, graphics, and concrete scenarios - makes design more accessible to user involvement than a purely discursive medium.

Finally, design is inherently multi-faceted. Designers are bricoleurs rather than polymaths. They work with 'found concepts' as much as 'found objects'. They borrow from other sectors and professions, and work with both. With their working practices determined by achieving practical outcomes, they are by nature inter-disciplinary, assembling teams of relevant expertise according to the task in hand.

All these characteristics make design, a potentially rich methodology for developing systems of open welfare, or 'full engagement', to use Wanless's phrase. The RED team has previously tested the methodology with some success in the areas of education, citizenship and criminal justice. The ideas of co-creation however, are no more than a proposition to be tested in practice.

The first part of this report is concerned with the outcomes of our work on redesigning health, the second with the experience of employing design to rethink healthcare and the challenges that re-thinking healthcare pose to design. The first is a narrative about design in health, the second a narrative about health in design.

The test sites we chose were in Bolton and Kent. In both cases there were public bodies interested in the idea of 'open welfare' and in linking what we were proposing to the innovations in which they were already engaged. In Bolton, the hospital and the primary care trust (PCT) wanted to see how the concept might apply to the treatment of chronic disease. In Kent the County Council's interest was in prevention. We saw these as two aspects of a common problem.

Diabetes in Bolton

Open welfare

More than two million people in the UK today have diagnosed diabetes. At least a million more - 'the missing million' - are thought to have diabetes but do not know it yet. In Bolton alone, 29 people are newly diagnosed with diabetes every week. Nearly 11,000 are already living with the condition - 1 in 20 of the town's adult population.

In its early stages Type II diabetes can be managed by diet alone. As it progresses, people must take oral medication and eventually insulin. The effects of bad management may only become visible after many years but involve loss of eyesight, heart disease, kidney and liver failure, and nerve-ending degeneration resulting in limb amputation.

Bolton

Bolton has one of the best diabetes services in the UK.¹¹ Despite this, the Bolton Diabetes Network estimates that 80 per cent of those people diagnosed with diabetes do not manage their condition adequately. The question is why?

Diabetes is not an easy condition to live with. Quite apart from medical compliance, managing diabetes affects people in many areas of their everyday lives.

People with diabetes and their families have to choose the right food to buy and cook. Refusing or having to ask for food at social occasions is embarrassing. Having to take time off work for numerous medical appointments is awkward. People must learn their body's signals that blood sugar is high or low. They must check their feet for lack of sensation, take their medication, test their blood and renew their prescriptions. They must find time to exercise regularly, and if they smoke, to quit. In short, once diagnosed, people with diabetes must significantly change the way they live their lives.

These changes cannot be delivered through consultations. The medical system's structures and procedures are geared to identifying the disease, prescribing and supplying the necessary drugs, advising on its technical management, monitoring its progress, responding to emergencies and complications, in order to reduce the risk of recurrence, disability and premature death. These cover 10 of the 12 standards of the National Service Framework.

Yet the onset of the disease and the course of its development is determined by the way individuals treat their condition and live their lives, and in this respect the person with diabetes is no longer the object of treatment, but the subject, no longer a patient but a self-directed individual. A person with diabetes spends on average six hours a year in consultation with medical professionals but more than 8,000 hours self-managing their condition.

Diabetes

Diabetes exemplifies the problems of chronic disease for contemporary healthcare systems. It is rising steeply. Internationally the rate of diagnosed diabetes has doubled in the last twenty years and is forecast to double again in the next twenty. In the UK the curve has been even steeper with the rate for men rising by 66 per cent in the past decade and for women by 89 per cent. It is the epidemic of the 21st century.

Diabetes is a disease where inactivity and poor diet reaps the whirlwind in later years. Type II diabetes (which accounts for 85 per cent of all cases) generally does not appear until middle age (40+), and is most common for those between 65 and 74. So although the rate of diagnosed diabetes for all adults is just under 4 per cent, for men aged between 65 and 74 it is 12 per cent, with a further 7 per cent undiagnosed. For men of that age there is close to a one in five chance of getting diabetes, and the chances are higher for those in lower socio-economic groups and ethnic minorities, particularly Asians (for whom the rate of diabetes is six times the average).

Type II diabetes is a disease strongly correlated with life-style (smoking, high alcohol consumption, poor diet, low physical activity) and with factors such as obesity, raised blood pressure, and high cholesterol. If it is caught early (in the pre diabetic stage) it can be reversed, but later it can only be contained. Failure to change diet, smoking and activity levels or take the recommended medication, results in a range of complications.¹⁰ Each of these can be seen as a failure of treatment at an earlier stage, as can the onset of type II diabetes itself.

The majority of those with diagnosed diabetes attend their general practice regularly, and an estimated 60 per cent attend hospital annually as an outpatient, and 20 per cent as an in-patient (both for diabetes and for associated diseases). Caring for those with diabetes alone accounts for 5 per cent of all NHS expenditure and 10 per cent of hospital in patient costs. Both figures are forecast to rise over time.

The issue for a healthcare system is three fold:

- Prevention, to avoid the onset of diabetes, and to forestall its complications once it becomes irreversible. Over 40 per cent of diabetes in men remains undiagnosed.¹¹
- Day to day management of the disease and of diabetic emergencies.
- Identifying and treating complications as and when they arise. This involves questions of lifestyle, of diagnosis and testing, of patient self-management, and of acute treatment.¹²

Diabetes in Bolton

Bolton has a population of 265,000 and a level of health much poorer than the national average. There are a high number of people dying from coronary heart disease and strokes, and a much higher proportion suffering from cancer, mental illness and diabetes.

In 2004 the NHS registered 10,500 people with diabetes in Bolton, or 5 per cent of those adults over 18. Its service for treating them is regarded as among the best in the country. There is a group of specialist diabeticians, and a hospital and PCT leadership, committed to a distributed system of diabetes care. They have established a specialist diabetes centre, now under the control of the primary care trust (PCT), which has taken over many of the responsibilities formerly carried out by the hospital. They have strengthened support for general practices in providing diabetes support services, and the PCT now runs seven general practices directly to ensure a good service.

There are a substantial number of front line diabetes specialists, including practice nurses, district nurses, dieticians, podiatrists, pharmacists and a new group of trainee support nurses. Its local authority and its PCT share the same boundaries, and have made two joint appointments to further the integration of preventative and social care policies. There is a strong Diabetes Network of the main public and voluntary stakeholders that co-ordinates policies and a cross cutting Diabetes Implementation Team of 14 professional specialists and two patients.

In spite of this the number of those diagnosed with diabetes continues to rise by 10 per cent p.a. and is forecast to reach 15,000 within four years. As many as a quarter of those with diabetes remain undiagnosed.¹³ Of those who are newly diagnosed, 50 per cent are already suffering complications, indicating that they have been living with the disease for some time. Diabetes is on course to affect 15 per cent of adults over 45 by 2010, with much higher rates for Asian adults.¹⁴

Existing preventative measures appear powerless to stop the dramatic increase of the disease. Testing the at-risk population for glucose intolerance (the stage before diabetes) is still only undertaken in a small minority of Bolton's general practices. For those with diabetes, the specialist team estimates that perhaps 20 per cent are good self-managers of their disease, a further 40 per cent are moderately good, and the remaining 40 per cent are intermittent or out of touch with the service. If the undiagnosed are taken into account, over half those with diabetes in Bolton have little if any contact with the NHS. Of those who are in regular contact, the majority are not effectively self-managing.

Rather than starting from the system of treatment, our work in Bolton focused on how to help people live well with Type 2 diabetes in their everyday lives. We wanted to look through the eyes of the individuals using the service and consider the experience of diabetes in that light. What we found was that spending time with people with diabetes and their families in Bolton, tracking their daily lives and concerns, and following their interactions with the health service made the issues surrounding self management clearly visible.

What we saw

Patients' experience of diabetes care

People refer to their diabetes check ups as their M.O.T. They feel they are repetitive and intimidating. Many confessed that they are not honest with their nurses or GPs and feel they are being told what to do. One man spoke of being asked the same questions and giving the same responses four times a year for 15 years. People feel processed. They are unsure of what they can ask, and often forget what they intended to talk about in the consultation anyway. The medical terms confuse them. Chronic care typically takes place in the same settings as acute care, and entails appointments, waiting rooms and one-on-one consultations, reinforcing a sense of dependency. The design team set out to make these consultations dynamic, collaborative and personal. They could take place in new settings.

Diversity

Everyone manages their diabetes in different ways. Any approach to supporting self-management of diabetes must take on board the complexity of different personalities and character types. Rather than dividing the diabetic population according to conditions or demographics, segmentation based on character type and need states would be more useful. After asking patients and practitioners to build character profiles and plot out 'diabetes journeys', however, we saw that although there were recurring character types, there was no one set path that people took to reach a point of living well with their condition. We needed a means by which people could define their current position and identify their own needs. The team developed a method of allowing people to co-create their own path.

Not on your own

While there are many advances in educational programmes on offer to people with diabetes, and increasingly sophisticated technology available for the self-monitoring of blood-sugar levels, there are significant gaps in help where it is most needed: in people's daily lives; help in choosing the right food to buy in the supermarket for example - not in a dietician's consultation room; or help in managing the effects of diabetes on one's social life - coping at parties, to take another example.

Most diabetes care focuses on the individual in isolation rather than as member of a unit of family and close friends. Although many say they would appreciate collaboration with others, group sessions organised by the Diabetes Network are poorly attended and there is little sharing of experiences. New tools and services could be designed to fit into people's lives and make it easier to live well outside healthcare institutions.

Between thought and action

We met a number of people during our research who were managing to live well with diabetes. Many of them were keen to help others. We also met some people who were doggedly acting on incorrect assumptions, for example that 'getting straight onto the stabbing (insulin injections)' was the answer.

The majority of people, however, were 'knowing strugglers' – people who knew what they should be doing, but for one reason or another, were unable to put that knowledge into practice. This is where an intervention would have greatest effect.

People felt able to be open with our design team because we weren't medical professionals. The design techniques we used in our research uncovered some latent issues, such as the need for a tangible sense of progress. Many people remained in denial of having diabetes and 'cheated' their regimes because they could see no tangible benefits of sticking to it. Any progress they were making to slow the condition's onset was invisible to them. The assumption that people will manage diabetes because they know it will damage their health in the long-term is similar to the assumption that people should want to quit smoking. The future is intangible, and there are few short-term incentives.

For this group of people, the question is not about better diabetes education, but motivation to act on their existing knowledge.

Prototyping solutions

Making problems visible and people's experiences tangible gave us a sound basis for co-designing solutions with patients and practitioners that considered the patient's needs in terms of their daily life as much as their medical conditions.

1- Agenda cards

Together we developed a tool that would make consultations more dynamic, collaborative and personal. The Agenda Cards reframe the interaction between patients and professionals, giving the patient the agenda. The cards contain a set of statements like 'There's the wrong food in the cupboard'. When used in consultation with a medical professional, hidden barriers to effective self-management are revealed, as patients pick out which cards are most important to them. Rather than following the usual checklist held by the medical practitioner, the patient's own priorities are made clear. The cards facilitate the co-creation of a personal plan of action.

Prototyping the Agenda Cards with people, their families and practitioners highlighted their value. The cards brought hidden barriers to the surface and permitted people to talk about things they didn't think they could mention. They gave the agenda to the patient, and that meant that they saved time – professionals were able to get to the heart of the problem quickly in consultation.

The cards are adaptive – patients can deal themselves a new hand at various stages of their progression. The reaction from patients was positive – they found the cards intuitive to use and liked the idea of having their own set. While the reaction from some professionals was also positive, some felt that using a deck of cards would undermine their professional authority. Once they had seen the prototype in action, however, many became converts to the idea of trying it out. Some of the nurses were excited to get back to holding useful dialogue with their patients in consultation, rather than simply entering data into their records. Many nurses saw the opportunity to adapt new roles beyond assessment with the time the cards freed up in the consultation process. A thousand packs of cards are now being further tested in Bolton by GPs and the Diabetes Centre.

2- Life coaches

Many of the people struggling to put their knowledge of diabetes care into practice picked out the card that said 'I need someone to coach me through this'. And so we tested out a service in the form of a 'life coach' for people with diabetes. We called them Me2 coaches, and their job was to help people in making changes in their daily lives.

Coaches are experts in enabling people to make decisions and take action rather than experts in medical practice, and are chosen by patients from an independent network. We used a set of mock 'coach profiles' in sessions with patients and it was clear that this ability to choose one's own coach was crucial to the way people responded to the proposed service.

Me2 coaches provide the support needed for people to act on knowledge and maintain motivation through home visits and telephone calls. They make use of web-based tools to help people visualise and understand the progress they are making. Although there is no person-centred accounting in the NHS, we estimate that the cost of nine months intensive coaching in one year compares favourably to the costs of someone becoming insulin dependent.

3- Connections on the web

We met many people who had developed useful ways of managing their condition, and who wished to be able to help others in the same situation. The Diabetes Blog is a peer-to-peer platform that allows patients, their families and professionals to develop and share strategies for living well with diabetes. It is edited and managed in an open style by all participants and is linked to the Agenda Cards. This immediately raised concerns of quality assurance of information – an indication of issues that arise from the relaxing of professional control.

4- New services

Together with patients and professionals we envisaged – in the form of short scenarios – new services for people with diabetes at the point of need. These were inspired by a range of services available outside of the medical field, including reality TV programmes aimed at turning people's lives around, like Wife Swap and What Not to Wear, and brought fresh thinking to diabetes care. Many of these new services could be offered by third parties such as supermarkets and local businesses and would grow from demand highlighted through the cards and the coaching service.

This new framework provides a platform for people to co-create services with professionals. Simple and cheap tools like the Agenda Cards can quickly be designed and implemented and have the potential to radically alter the nature of current interactions towards greater responsibility and engagement on the part of the patient, and collaboration on a more equal basis between patients and professionals.

Many of the problems of preventing and managing diabetes are similar to those of other chronic diseases. The work in Bolton suggested new tools and types of provision for diabetes care and self-management which have relevance for the management of chronic disease and patient involvement more generally.

Activity in Kent

Context

Obesity and chronic disease, especially among older people, are emerging as major health challenges in the UK. A key factor underlying these problems is a trend towards less physically active lifestyles.

The benefits of physical activity are clear. Studies show that 6-12 miles of walking per week reduces the risk of premature death by between 20 and 30 per cent. A whole range of diseases such as heart disease, diabetes, and strokes, as well as depression, lack of confidence and social isolation can all be positively affected by staying active.

In Kent our subject was how to encourage activity. This took us outside the health service to the County Council who were interested in new ways in which they could promote more active lifestyles, particularly among older people. Although we based our research on Park Wood estate in Maidstone, the Council was interested in solutions that would have a wider relevance than a purely community-based initiative.

In government policy terms, a decline in activity would be considered a public health issue. Yet there are limits to what can be delivered centrally. Mass campaigns can be delivered via the media and intermediaries such as GP surgeries, schools, and local authorities. Regulations can be passed and facilities and tools funded (such as more playing fields, or better pavements and street lighting or walking maps and pedometers). But getting people to exercise is not like providing clean water, and these interventions can only go so far. To influence public health one must also influence innumerable private healths.

This was the context of our work in Kent. We wanted to explore, through a user-centred design process, what mileage there was in approaching the problem from the viewpoint of individuals and their particular drives and circumstances in relation to activity, rather than from the mass promotion of an active lifestyle.

User research

As in Bolton, the starting point was spending time with people in their homes and understanding what activity meant to them. This provided insights from people's everyday lives, their patterns of behaviour, interests and aspirations. Again what was most immediately striking was the differences between people - in their economic and social circumstances, in their physical capacities, their daily routines and their interests. This informal time spent with residents helped the design team to gain a fresh perspective on some of the less obvious common drivers and hurdles to getting or staying active in Park Wood.

Activity

The ways in which people have traditionally been active have largely been mechanised away. Daily living fifty years ago involved activity equivalent to a marathon a week more than is required today, not least because of the growth of labour-saving devices in the home.¹⁵ Mechanisation has had the same effect at work. Only 20 per cent of men and 10 per cent of women are now employed in active occupations.

In transport, the rise of the car has meant the eclipse of the bicycle. In 1952 the British cycled 23 billion km annually. Fifty years later we only manage four billion km. Even walking has been in decline, down 25 per cent in the past 25 years. Today fewer than half of young children walk to school.

Activity in short has been designed out of the daily routine, and society has to think how to re-invent it. This is the age of the gym, the exercise bike and the running machine. The UK market for health clubs and leisure centres reached £3.2 billion in 2003, and is set to outpace consumer spending for some years to come.

Yet those using these facilities and achieving healthy levels of activity are a minority. According to the Chief Medical Officer, in 2003 only 37 per cent of men and 24 per cent of women achieved the recommended levels of activity (30 minutes moderately intense physical activity on 5 days of the week).¹⁶ The prevailing level of physical activity remains low, and is a major factor in obesity and in 20 other diseases. Nearly a quarter (23.5 per cent) of the English population are now categorised as obese with all the attendant risks (and from the Government's point of view, costs) that this entails.

People who have a physically active lifestyle reduce their risk of major diseases such as coronary heart disease, stroke and type II diabetes, by up to 50 per cent. Encouraging physical activity has therefore become a central priority for the Government's policy of prevention.

Activity in Kent

In Kent the most recent health survey of 8,071 respondents found that the level of recommended exercise was even less than the national average. Only 17 per cent of people said they were taking the recommended 30 minutes five times a week, and 42 per cent said they exercised less than once a week.¹⁷

The reasons given for the low level of physical activity were the following:

- Lack of leisure time (particularly for men of working age)
- Illness or disability (the principal reason for those over 75)
- Lack of incentive (notably for middle aged men aged 45-64 and women aged 25-44)
- Lack of money
- Lack of interesting activities
- Lack of facilities at work or in the locality
- Lack of transport (primarily for those under 25 and those over 75).

Kent County Council

Kent County Council has been in the forefront of developments to create personalised services and promote policies of prevention. In health, they have introduced telemedicine technology imported from the US. They are turning schools into centres for promoting healthy eating, and are pursuing policies to increase employment safety and accessibility on the grounds of their contribution to health. They have also introduced a web-based method of needs assessment, on the basis of which those who are entitled to social services are credited with the money that would otherwise have been spent on them, which they in turn can spend either on services provided by the Council or on other services which they consider would be of greater benefit.¹⁸

In 2004, in line with these policies and in response to the health survey results, the Council discussed with the Treasury the inclusion in its forthcoming Public Service Agreement, of a target to raise the number of elderly people in the County aged 50-70 meeting the Chief Medical Officer's recommended activity level. It was interested in how a design-led co-creation approach would further this project.

Park Wood

The area the Council proposed for the design initiative was Park Wood in Maidstone. It is one of the most deprived areas in Kent, with a population of 4,000, rising unemployment, high benefit take-up, a substantial proportion of single parent families, and of people unable to work. The County had been pursuing an integrated "supporting independence programme" on the estate, which included the establishment of a health living centre (funded by the PCT), and the creation of a community school.

The following were some of the relevant features of the estate:

- The majority of the housing was public, but was in the process of being transferred to a housing association
- Twenty eight per cent of the population had a limiting long-term illness or said that there were in poor health, and consequently had low levels of activity
- Park Wood had a relatively good physical infrastructure for activity, in marked contrast to many inner-city estates: 60 per cent of the houses had gardens; there were reasonable pavements (though no cycle tracks); an extensive open space ('the rec') with woods; a football pitch; a bowling green (that used to be a key venue for the County); a basket-ball court and sports centre; and the town's main leisure centre a mile and a half away. However many of the facilities had become unusable (arsonists had burnt down the bowling green pavilion and the green itself was unusable, as was the basket-ball court, the football pitch cost time and money to book, and was open to dogs).
- There was a good deal of lower-level activity of a routine kind, walking dogs, going to and from the estate's shopping precinct and the nearby supermarket, some walking to school (38 per cent of households had no car). Although there was an industrial estate bordering Park Wood, nearly two-thirds of the economically active travelled to work by car and only 13 per cent went by public transport.
- There was a strong informal economy of micro group activity, of mutual support and volunteering. Someone had started a Green Gym to help people with their gardens. The local school had a vigorous parents group and a headmistress who wanted to develop a community garden at the school. Neighbours walked each others dogs or gave lifts to the supermarket.

Hurdles

People find exercise hard to prioritise. For many it is a different world, something that happens 'in the gym' rather than in their day-to-day lives. Cost, time, and childcare are all barriers. For some injury or disability creates a vicious circle of inactivity. Many people feel too embarrassed by their size or physical abilities to go to a class. The local environment itself can be a barrier. Many older people feel vulnerable and too intimidated by their surroundings to go walking on their own.

Poor lighting and pavement surfacing, a lack of interesting destinations or routes and bad weather put people off walking. The cost and hassle involved in hiring facilities, and increasingly complex insurance measures, make it more difficult for people to be proactive. People avoided initiatives run by local organisations they perceived to be 'cliquey'. Those who wanted to be fit often tired quickly of a certain activity.

Drivers

'Having someone to go with' is a big driver for activity, as is linking physical activity to an interest such as dancing or local history. Many of Park Wood's residents are active in a low-key, informal kind of way – gardening, walking to the shops or walking the dog. These activities could be more effective for staying fit. Peer pressure from children, family, friends or under-exercised dogs was what got people going. Social networks, between neighbours and family living on the estate were particularly strong.

Many people had been active in the past and felt they were latent exercisers, waiting for something to trigger them into action. When probed a little deeper, many people revealed desires to try out new things and activities such as dancing that they had never dared to do. Proximity to facilities was important too. Opportunities to exercise could be triangulated in terms of timeliness, interest and proximity.

People who were already active, had a variety of 'spurs for action' - personal wellbeing, guilt, competitiveness, a 'can't-sit-still' constitution, stress relief, efficiency (getting from A to B on a bicycle, for example), fun. Activity as a social occasion was the strongest driver. 'You can't really have a good laugh at the gym,' people said.

From these conversations it became clear that anything too fixed or formal wouldn't work. We needed a system that would help people to do whatever they wanted, in whatever time-frame suited them. Looking at the estate as a landscape of opportunities for activity showed that there was plenty of interest, willingness, and capacity for activity. There was a significant 'volunteer' economy on the estate, with people donating their time and skills. The estate was relatively rich in facilities, particularly open space, even though some of it was dilapidated. What was needed was a way of connecting these elements in a useful way. This was the design challenge.

Mobs

Inspiration came from new developments in social software, cultural phenomena like flash mobbing and old social-selling models like Tupperware parties. Connecting opportunities, tapping into people's existing interests, like gardening or dancing, making use of informal activities like walking the dog gave birth to **Activmobs**.

Mobs are small groups of people who carry out activity together on a regular basis. They are

connected by the Activmobs system. Activmobs is a platform for activity. It provides web-based tools to help people find, suggest and start mobs, to monitor their progress, set goals and reward commitment. It provides support roles to motivate mobs and ensure their activity is effective.

Resources are immediately available to anyone who participates in the system. Forming a mob gives you vouchers and discounts, used to remove barriers to exercise like facility hire, childcare and transport. They also give you hours with a trainer, who helps your mob to set goals and shape your chosen activity so that it is effective in improving fitness.

Activmobs matches interests, and builds on the positive peer pressure of groups. A set of wellbeing cards help people to recognise the tangible benefits of activity: sleeping better, improved confidence and flexibility. This form of self-assessment is based on what people themselves want to know. Tools are available to help mobs to visualise their progress. They might show, for example, that collectively the group's waist has reduced by six inches.

The design team used a unique method to develop the concept of Activmobs. Rather than designing the whole system from the outset, we carried out five weeks of live 'experience prototyping' with Park Wood residents to determine how the system would operate. To do this, people from Park Wood set up a number of proto-mobs, with the design team playing the role of the system and responding to various needs and issues as they arose. This meant that the concept evolved through the participation of the 'mobbers' rather than from the assumptions of the design team. For example:

- **Backmob**, two older couples each with various back injuries and conditions, used their mob to relieve aches and pains. Through their participation the system grew to provide hours with a personal trainer who offered reassurance and professional support in setting the right exercises.
- **Welliemoob**, a group of mums who walked their dogs together after dropping the kids off at school, highlighted the importance of doing things as a group – we responded by providing group goals, progress tools and rewards.

Offering start-up packs through an advert in the local press showed the power of viral marketing and interestingly, uncovered a largely untapped resource of pro-am trainers waiting to donate time to the system in return for help with professional fees. New roles appeared in the system in the form of mob-motivators.

Assessment and incentives

Two issues – of measurement and incentives featured strongly. A workshop with statisticians from Kent County Council, sports psychologists, policy analysts, service designers, social software developers and doctors threw up interesting insights.

The first was on self-assessment. While Kent County Council's targets would be fulfilled by measuring fitness levels as a result of Activmobs being live in the area, the kinds of tests involved – such as VO2 Max tests, and heart-rate monitoring – would be strong disincentives to participation. The issue was resolved by the local GP who pointed out that surely the best measure of fitness was whether the person was feeling fitter in themselves.

This gave rise to self-assessment and self-monitoring built into the system in the form of a set of 'well-being cards' on which people mark how much more flexible they are or how much better they are sleeping. One member of Backmob said that she just wanted to be able to reach the skirting boards again to clean them. The cards contain measurements that are meaningful to people, rather than to statisticians, and therefore act as a form of incentive in themselves.

Incentives were the second insight. Most people drop out of an exercise routine after between three and six months. Rather than taking a carrot and stick approach, we wanted to find ways of ensuring that Activmobs provided sufficient incentives for people not just to start but to continue over the long-term. We agreed that rewards based on performance could be counter productive and were wary of extrinsic incentives outweighing intrinsic ones.

In the end the system arranged for self-set rewards to encourage commitment. Set your mob a goal – say to meet every week for three months - and select a reward you can enjoy as a group. The rewards are all related to wellbeing and trying new things, like dancing lessons or a day at the spa. The most important aspect, however was the need to design a system that is motivational in and of itself – one where joining is aspirational and participation reinforces internal motivations.

Coaches

One other feature of the system which has proved to be its own incentive was the service of a fitness coach. She began as an adviser to the RED design team, and finished as a coach to the mobs, a 'home health' rather than a home help. To begin with it was unclear what if any professional help was needed for mobbing. Mobs were collaborative, but were original envisaged as standing independently of professionals. But it transpired during the prototype that for some (those with bad backs) her advice was critical, and for others it was the coaching techniques of stretching existing activities and making activity enjoyable that were most important. Given that she would coach in groups, we found that individual mobbers could have 16 hours of annual contact time with her for £100, less than a tenth of the annual per capita costs of the health service.

Light organisation

Activmobs is self-organising. Natural leaders in the system can become Mob Motivators but ownership of the Activmob platform lies with the participants, rather than the local authority or the NHS. Activmobs is co-created by the mob community. The look and feel of the system reflects this. It must not feel like a council initiative, nor as if it is run by any particular personality, but should rather feel autonomous and easy to opt in to.

Activmobs is quickly scaleable across other regions, and is strengthened by increased participation. Activmobs could be developed as a not-for profit social enterprise, potentially subsidised by revenue-generating versions such as Workplace Mobs, a service to create a healthy workforce based on the Activmob platform and tools.

Conclusion

One of the principal conclusions of the prototype was that the take-up of an activity depended first and foremost on the way the system is designed, the lightness with which it is organised, and the relationships and impacts it has on the participants. Five principles for an attractive system emerged:

- Take up of the activity should be easy and not offer a major challenge to existing routines
- Exit should be easy (ie small initial commitment)
- It should provide immediate positive feedback (either through fun, feeling better, or meeting some other immediate need, or desire for personal fulfilment)
- It should be collaborative, with difficulties being shared and mutually worked through, either by other participants and/or with the help of an adviser/assistant.
- Economic incentives should act as a reinforcement rather than a primary driver.

The project laid the grounds for a possible support service that could encourage activity. It did so by exploring the 'open form' question, of whether 'spaces' could be created so that the people in Park Wood generated their own activity, starting from where they were at, in the form that fitted their personalities and interests, and in the company of people they chose to be with. That was its immediate task. But in shaping an answer we saw elements of a system emerge which potentially had a wider significance.

Design for engagement

The user research in Bolton and Kent led to design specifications which were emotional rather than technical in nature. Designing for engagement means designing around what makes different people tick, why they act, what drives them. The rational and the functional are part of this, but only a part. Common to the two prototypes were a number of themes that serve as a summary of points that need to be kept in mind when designing ways for people to engage in their own healthcare.

Motivation

In terms of chronic and preventative healthcare, motivation is the new medicine. People have to choose to make changes to their lifestyles – they have to opt in. That means that any service must be designed to appeal to people's aspirations. Participation in a service or system should be motivational and rewarding in itself. The system should provide triggers for action: by aligning opportunities to interests, by being experiential rather than educative, by building on existing social drivers. These aspects can be designed into systems, services and experiences.

Action

Experiencing another way of doing things is one of the biggest motivators for lifestyle change. This is the reasoning behind the recent spate of reality TV shows that place people in new situations before allowing them to reflect on what they have learnt. In our work, rather than start with education, we have begun with experiential action.

Activmobs first triggers action, then highlights the benefits of that action by encouraging people to track progress and reflect on it, and engage further in the mob development. We felt that many people with diabetes would benefit from a glimpse into an alternative way of living their lives; to give them the strength of will to continue.

This experiential action maps onto social cognitive theory, inverting the inform-decide-act process to act-reflect-continue. Many of the people with whom we worked were well informed about what they should do, or screened out information whose implications they could not or would not do anything about. The problem for all of them was the doing. This suggests that health promotion services should encourage the designing and staging of positive experiences. Learning by doing may be as, if not more, effective than traditional educational programmes.

Lifestyle fit

Services in other areas of our lives, such as flexible banking and concierge services, are increasingly designed to fit into our busy schedules and preferred locations. The same should apply to healthcare. Lifestyle changes cannot be delivered through institutions with their own priorities, appointments and opening hours. Not only do we need to match service provision to people's own interests and daily routines, but we need to integrate them at the point of need – at the point at which they become relevant to daily life. Dietician services appear in the supermarket aisles, for example.

Activity need not be something done separately in the gym but can be part and parcel of a social occasion. To make this work we must first understand the complexity of people's lives and behaviour patterns and then identify opportunities for the integration of support and new services. A design approach to their development can be decisive in ensuring their success.

In control

A sense of being in control of your own health is an important aspect of being able to take greater responsibility for your healthcare. This means that self-monitoring becomes paramount, as does the ability to make choices. Tools for self-monitoring are not simply about technical measurement of blood-sugar levels, for example, but can also be designed to help people to become more self-aware, and understand the effects of patterns of behaviour on their body as a system.

Being in control of a chronic disease, rather than it controlling you, is central for chronic disease self-management and means changing the perception of care from being about illness to being about wellness. Many current services are designed around an illness and dependency model which is translated into the design of their experiences and settings. These can be redesigned to put wellness to the fore, and to give control to the individual. BUPA's 'the patient will see you now sir' promotion is a good example of this change of emphasis.

Tangible progress and meaningful feedback

Making changes to the way we live our lives is difficult, slow and frustrating. Motivation to keep going needs to be supported by a tangible sense of making progress. Because the benefits are often long-term, people feel the need to see some short-term gain.

If an individual has diabetes, for example, any headway made against the onset of the condition is invisible. The only indication of successful progress is a lack of symptoms, meaning that people tend to push at the boundaries of their eating patterns to test out what has an effect. Measuring blood-sugar levels is one way of indicating progress, but can easily create medicalised behaviour – a more holistic way of measuring progress is required.

Similarly for fitness and weight loss, which can take time, the immediate benefits need to be made visible and tangible to people to motivate them to continue. Studies show that the most effective weight loss programmes are ones where people are able to track their progress in detail.

Measures must also be in a form that is meaningful to people. While technical jargon and statistics will appeal to a minority, for the majority we must find new ways of registering progress.

Co-authorship

As Channel Four's 'Jamie's School Dinners' showed, people are reluctant to engage in changes to their behaviour patterns – such as eating new and unfamiliar meals - unless they have had a hand in making them. Similarly co-authorship of healthcare is crucial in the engagement of people in taking action.

While the current rhetoric in healthcare around patient-centred care and partnership between patients and professionals is sound, the challenge is to make that aspiration real. Project managers can be heard to sigh at the thought of 'getting the patient involvement people to look over the project', and patient and public involvement (PPI) has become a separate section at conferences as people struggle to 'fit it in' somewhere.

Our experience is that unless situations and tools are consciously designed to properly facilitate partnership between patients and professionals, then PPI remains little more than

good will. We must create more tools to allow people to put forward their own agenda, and design ways to breakdown the traditional barriers between patient and doctor.

People's own experiences become useful currency in a co-created system, and forums are needed where people's knowledge of their own behaviour patterns and strategies are considered together with medical knowledge, and where healthcare 'content' is co-authored.

Collaboration

One of the most useful concepts in our work has been to consider people not as isolated individuals, nor as 'communities' in the 'community regeneration' sense, but to consider people as part of multiple communities of individuals – made up of family or social units, or virtual communities of interest.

This means making use of existing social relationships and circles of care to positively reinforce good health. Networks like Weight Watchers and Alcoholics Anonymous are successful because people benefit from exchanging experiences with others in similar situations, from moral support and group motivation, and feel rewarded by helping others.

Facilitating networks of like-minded individuals, either with shared values or complementary skills, provides opportunities for collaboration and the sharing of resources. Activmobs work by connecting people with common value sets and goals and having them share resources that would otherwise be difficult to finance and distribute. Keeping in mind the notion of multiple communities of individuals is important if networks of collaboration, and peer-to-peer knowledge sharing are to be successfully designed.

Support

An important element of our work has been the emergence of the need for support - enabling people to act on knowledge and motivations. Education and advice only went so far to help the people we met. They needed support in making decisions and emotional, psychological, and motivational support in carrying them through. We saw it coming from friends and family. We saw it coming from medical professionals, less in their capacity as medics, and more as inspirational figures. We saw it in the form of group support and virtual connection. This human interaction is central. In a formal sense it can be developed into professional or pro-am roles, as with the diabetes 'coaches' in Bolton or the 'mob motivators' in Kent. In an informal sense it can be facilitated through tools and virtual networks of support.

These themes emerged from our work in the two test sites. The question is how they can be articulated at the level of a new system.

Open Health

Design as a methodology mixes empiricism and imagination. We start from observation, about how people live, what moves them, and how they cope. On this basis designers imagine solutions, which are tested and retested as prototypes, in a continuing interplay of the experienced and the imaginary.

As we worked in the test sites we were aware not only of the NHS as a system, but that the issues and ideas which arose from working with users, suggested the elements of a quite different model for the support of self-care and prevention, one that contrasted strikingly with that developed for acute care within the NHS. We have called this emergent system Open Health.

Open platforms

Open Health draws on a number of strands of systems design that have the common feature of dissolving the role of central direction in favour of distributed action. A platform provides a common space for action together with a set of rules of engagement. Platforms can be physical and virtual - like those developed by Amazon and eBay, or on a more modest scale the web-site and magazine we prototyped in Kent. As we put it earlier, the design task is not to design a service - whether or not it is provided free or sold on the market - but rather to design a platform that enables activity to take place. The platform is a stage for which the audience write the script and become the actors.

The activity that takes place on these platforms can be facilitated. It can be influenced by incentives and by the quality of design. But it cannot be determined or controlled. This is the key point. An open system moves away from the model of an organisation which seeks to centrally determine what activity should take place, that separates conception and execution, and lays down rules, accompanied by disciplines and incentives to make sure that it happens.

In a centrally directed system of this sort - which was the predominant organisational model of the Fordist period - complexity is gathered into the centre (reflected in higher overheads) and can only handle simplification at the margins.²¹ In health it means working with the notion of undifferentiated patients to whom it applies norms and probabilities, and treats by standardised procedures. As we suggested in Chapter I, it is a mass service, with its information systems, organisation and finance structured round types of goods or services - in healthcare round procedures and the specialisms of disease.²⁰

Distributing complexity

A system to encourage active health cannot simplify individuals in this way. For individuals are themselves complex systems. Each has their own personality, their own pressures and aspirations, a mix of mental and physical conditions (so-called co-morbidity), and their own social context and network of relationships. They cannot be defined by their disease, or classed as patients because of their relationship to a service. If individuals are now the central agents, then services must be defined in terms of support for them rather than vice versa.

A system constructed round self-determined activity has to take account of differences. It reverses the principles of centralised organisation by starting from the complexity of the margins (individuals) and simplifying the centre. It does so by replacing the functions of the centre by lateral connections and new services, by protocols and mechanisms of synthesis. Its focus is on the design of platforms and tools for accessing and using those platforms not the choreography of what happens on them.

Closed systems are marked by gatekeepers and restricted access. Open systems on the other hand, like those that have flourished with the web, such as Linux, Friendster or Freenet, thrive on participation rather than being swamped by it. Access is easy, open and low cost. Participants are only vetted after they are involved.²¹

The notion of 'openness' then is about the freedom of action that is possible on the platform, and of the ease of access to that platform. It is also about its path of development. This, too, is open, the result of the aggregation and interplay of the activities, relationships, and services that take place on it. It is this which allows the centralised complexity of a command and control system to be simplified and dispersed.

This idea of open systems has much in common with those of complex, adaptive systems as developed in biology, ecology and engineering. They emphasise particular characteristics of such systems, such as self-organisation, distributed intelligence, connectedness, the importance of positive and negative feedback, and the mutual influence of individual actions. Much of the biological and ecological work is on how these systems work without a central command, what patterns they display, and how they adapt as systems.

Contrasting logics

These ideas are suggestive for the design of Open Health systems. They do not provide a blueprint, not least because we are dealing first and foremost with human systems, which have their own forms of chaotic behaviour²². What follows is a set of design principles for an Open Health system that have been prompted by our work and which can be seen as 'emergent properties' of the new system, to use the terms of complexity theory. As with the characteristics of open systems as a whole, each of these properties emerged in contrast to the structures and processes that characterised the system for acute care as it has developed in the NHS. They appeared as contrasting logics. Many in the NHS are themselves engaged in developing open health practices. But they are doing so in tension with a structure constructed for other purposes.²³

We distinguish five of these contrasting logics-

1- System architecture

Open systems are structured first and foremost on the distributed principle, in intelligence, resources and decision taking.

2- The health relationship

In traditional healthcare systems the primary relationship is between the medical professional and the individual patient. Knowledge is concentrated with the professionals, and is transmitted to patients serially, with little connection between patients. Active health and self-care requires both a new professional-lay relationship (co-creation) and a much more extensive web of informal relationships (collaboration). For active health, the quality of relationships is key.

3- The service logic

The NHS is structured to deliver linear or sequential services to users. The users are seen as consumers of the service, and as such, through the service reforms, are to be assured the rights of other consumers - choice, information, quality guarantees, and stakeholder representation. In a co-created model, users are the agents of their own health, and as such require the kind of support that any producer might receive - training in self care skills, advice, encouragement, tools, and facilities. Personal support becomes the critical service for self-care.

4- The organisational logic

A public health service like the NHS, run by a centralised organisation, and provided free at the point of delivery, has proved itself to be the most effective and economic means of delivering universal healthcare as a service. The economy of open health requires a more diverse, and distributed range of providers.

5- The economy of motivation

For an acute health service the problem is not how to motivate patients, but how to cope with service demand. Suffering is its own motivator. For self-care and public health, individual motivation is a more complex issue. A new economy of motivation is required.

These five principles build on and extend the propositions we set out in the RED paper (2004), based on the experience of the test sites.

The distributive principle

We found the distributive principle a powerful idea in health. For if the starting point for active health is individual agency, where the individual is the producer of his or her own health rather than a passive consumer of healthcare then there is a need to distribute resources, know how, advice and finance to provide him or her with the necessary support.

Distributed intelligence

The first resource is knowledge and the ability to communicate. The internet is already transforming the informational economy of health. In the past medical knowledge was concentrated in the medical profession, and conveyed episodically through brief one-to-one encounters between a designated doctor and patient. The internet and e mail have now made available multiple sources of medical information, and opened up seemingly unlimited possibilities for the sharing of patient-to-patient experience.

There is a UK website, www.dipex.org, which has already built up 1,200 narratives of patient experience, disease by disease, in sound, video and print. There has been an explosion of chat rooms for those with specialist conditions, often including a medical specialist. There are now 18 million cancer web-sites worldwide. From a situation where the problem was the limits to information and to contacts between patients, the problem has become a surfeit of both. The result has been an irreversible change in the relations of doctor and patient.

The potential benefits of this change are immeasurable. It is a condition for the emergence of a distributed, individual-centred system. It opens up access to the kind of medical and experiential information which is central to a person's sense of control over a chronic disease, and to his or her capacity to live with 'wellness-in-the-foreground' rather than 'illness-in-the-foreground'.²⁴ It provides the basis for learning about living with chronic illness not just for patients but for practitioners themselves.

How is this new economy of plenty to be negotiated? There is an immediate demand for intermediate editors, for guides and commentators. The Macmillan Cancer organisation is in the process of providing such a guide to the 18 million cancer websites. But the task is far too large for any one organisation. It is a general problem of the internet era, and already the pioneer dot.com companies are finding innovative ways of answering the question by codifying the patterns and experience of use as an aid to navigation and learning. In the words of Brewster Kahle, the inventor of a collaborative filtering technology bought by Amazon, 'Learning from users is the only thing that scales to the size of the web'.

A site such as eBay records the reliability of sellers by registering the responses of buyers, and also provides links to those with common interests like stamp collectors. Amazon suggests books of related interest on the basis of population-based buying behaviour. Slashdot has developed a filtering system for a bulletin board, through assessing contributions and rewarding good contributors by appointing them as assessors.

Just as NHS Direct applied the principles and technology of a call centre to traditional forms of medical advice, there is now the potential for an Amazon Health. It would carry information not just on particular treatment centres or specialists but help chart the web of health. For those with particular chronic conditions, there could be a whole range of recorded experiences of different approaches to treatment with links to relevant scientific research, and filtering systems based on use.

It would not mean the displacement of doctors, but a redefinition of their role, as interpreters and advisers. Similarly it would not mean the disbandment of the specialist centres of medical knowledge and setters of guidelines like the National Centre of Clinical Excellence (NICE). Rather the NICE methods and conclusions as applied to individuals would become contestable if the NHS quasi-market reforms are a form of perestroika, Amazon Health would represent glasnost.

Patient Opinion is a web-based system designed by Paul Hodgkin, a Sheffield GP, and being piloted in South Yorkshire. It collates patient experiences of being treated for particular clinical conditions at public and private hospitals in the area, and is designed to help patients choose their place of treatment as part of the Choose and Book system, on the basis of other patients' experience.

It is being established as a social enterprise, providing its services free, and financing its costs by selling data to Trusts and PCTs.

This transformation of the 'relations of information' has been led by the internet, but does not depend on it. In Bolton we estimate that 75per cent of its population does not use the internet. One potential health strategy for the borough would be to hasten the installation of a digital spine, plus cheap computers supported by teams of web trainers. Some of the functions of the web can be achieved through mobile phones or television, and programmes such as the Discovery Channel.

But even without these domestic technologies, the principles of distributed information can be much expanded. GP surgeries and pharmacies could provide guided internet searches, following the lead of modern public libraries.

The above relates to chronic disease, but is equally applicable to lifestyle. There are already internet sites that promote activity and provide lifestyle advice and information (one Newcastle GP has established a local activity site called Idle Ernie which had one million hits in its first six months). Shops and supermarkets could become hubs for independent food information, particularly those providing a web-ordering service and home delivery.

Distributed access

Home delivery: what would this mean in health? After half a century of increasing geographical centralisation of facilities - from shops and schools, to power stations and town halls, there have been the first signs of a reversal. In Japan, home delivery of food is widespread and is undercutting supermarkets. In Britain, it is not just home grocery deliveries that are on the rise, but convenience stores which act as local spokes to a supermarket hub. Local councils are opening one stop neighbourhood offices linked to the council information systems. Bobbies are being put back on the beat. In energy and water, the new talk is of distributed systems. All of these are being made possible by developments in information and communication technology.

What of healthcare? In the past the logistical costs have been passed to the user. Hospitals have been centralised, entailing longer journeys for those attending them. Doctor's home

visits have been cut on grounds of economy. But here, too, there are signs of a turn. The shift of some hospital services to GP surgeries is a first step. The government is encouraging a second - the provision of primary care through pharmacies and walk-in centres sited in stations or near shops, as well as virtual access through NHS Direct. Many GP practices run neighbourhood clinics, and the digitalisation of patient information increases the scope for such local nodes, on housing estates, or in workplaces.

The development of testing and monitoring technology can take this further, either through the use of mobile testing equipment or through home testing and monitoring, which is itself on the verge of a revolution. We met a nurse from a practice in Worcestershire where they had introduced home blood-pressure testing to improve the levels of blood pressure control. Levels did improve, but strikingly they also found that some of those diagnosed with high blood-pressure, did not have it when testing themselves at home (the so called 'white coat effect'), and there was a notable fall in prescriptions and surgery time (results were logged by patients on a confidential website, and medical staff intervened on the basis of variance usually over the telephone).²⁵ We also talked to a medical systems specialist linked to home (night-time) dialysis and remote kidney-transplant monitoring which had transformed the lives of patients freed from the requirements of repeated hospital attendance.

One of our project advisers had experience of a social care project in Maine, where elderly people were connected through a video link, that allowed them not only to communicate with each other (and even share morning exercise routines) but was also open to two-way connections with social services staff.

The increasing use by GP surgeries of telephone 'touch ins' will be enriched by video links of this kind, as well as by services delivered over cable or other local digital channels. These are all examples of a new form of home delivery and distributed access which promise to reconfigure the micro work patterns of doctors and their relationships with patients.²³

Distributed feedback, innovation and learning

As with information systems more generally, feedback in the current medical model tends to be slow, expensive, and controlled by the profession. This is most striking in the system of healthcare innovation. The requirement for controlled trials as a condition for the introduction of new drugs and procedures requires studies lasting years, with costs running from £0.5 million to as much as £300 million for some proposed drugs. This mirrors the classic pattern of Fordist innovation, of large episodic innovation preparatory to mass utilisation. On the basis of the evidence of these procedures, a single body (NICE in the UK) makes recommendations for preferred methods of treatment.

There are few industries where innovation is so slow and so costly. The main reason is the potential damage caused by failure. As patients we are no doubt grateful that such thorough trials are undertaken before new interventions are used on us. But such a system of innovation is inappropriate to the field of open health. What is needed here is a more distributed and open ended system of innovation (a readiness to try things out) and a user-centred feedback system to register and circulate the results.

The first lesson from Kent is that any feedback on the effects of activity, any monitoring of results must first be of value to the mobbers themselves. The resulting prototype was a means of charting the impact of activity through qualitative ratings, completed monthly, and fed back like a bank statement every three months. In this case the mobbers generated their own feedback - whether they felt better from their activity.

In diabetes care, in place of standardised box ticking, the gathering, presentation and discussion of medical data could be co-created and constantly adapted. There is scope for a group review of individual progress (a user-centred version of Japanese quality circles). In mental illness, there are examples of patients conducting research on themselves both for their own benefits and to generate data that can be passed to the PCT. This idea of 'sousveys' self-research using professional research methods (the view from below) - in contrast to surveys (the view from above) - can increase a sense of user control at the same time as tracking the impact of self-experiments in treatment.

At the level of populations, there needs to be routinely collected data sets that reveal correlated movements. For example, a research study found that the replacement of low-rise housing for tower blocks in Hackney led to a 50 per cent fall in visits to the GP by those who had been re-housed. Person-centred data sets that track not only health conditions and healthcare episodes, but other life data like employment, housing, household composition, and benefit receipts, could be mined by software to trace the impact of personal changes without recourse to one-off surveys.

More generally, the recasting of the medical relationship in terms of learning would allow it to borrow many of the best techniques from modern education, such as the distance-learning techniques used by the Open University, the two-way use of video and audio as well as print, as well as the many ways of learning by doing and by experiencing.

The etymology of the word 'doctor' is the Latin for 'teacher', and just as teachers take on new roles in the modern learning economy, so the doctor's role in an open health economy would change to being an interpreter, a knowledge guide, an adviser and motivator - in other words a teacher.

GP surgeries could remodel themselves in the manner of the new wave Applestore in London's Regent Street, where in addition to a GP-style appointment system for computer fault diagnosis and repairs, one part of the shop is a lecture room with a free daily programme.

Our first design principle, then, is to think distributed. It will apply not only to information, to access, and to innovation and learning, but to the development of tools and skills, and to the system of finance. It does not erode specialism, but structures its production and distribution in a different way.

Co-creation revisited

A distributed economy of health - of intelligence, of resources and of access to services - reconfigures the topography of the health system as it presents itself to individuals. It puts new tools in their hands, it opens up new spaces, and above all it creates conditions that allow a whole range of human relationships that lie at the heart of active health to be recognised, extended and transformed.

Whereas pathogenic healthcare is centred round the provision of a service delivered by skilled medical professionals to de-skilled and passive patients, co-created health revolves round engaged individuals working alongside a wide range of medical and other professionals. It is a contrast between the scientific management of people as patients, and the collaborative action of patients as people.

A new medical relationship

The co-creation of health revolves first around a quite different medical relationship. The patient as person meets the medic as adviser. There is a shift in the locus of responsibility and control. In Bolton, those people with diabetes wanted a sense that they were in charge of how they coped with their condition, of the goals they set and strategies they followed. At its simplest they did not want to feel like cogs in a machine, but rather sought a different kind of relationship with the professionals.

One element of that relationship is joint planning of a personal strategy or service - often called 'co-design', and most concretely embodied in patient plans. The Agenda cards are in part a tool for dialogue in that process. A second element is co-production, where people undertake their own care in conjunction with professionals or produce elements of the service on offer. It was the problems arising in co-production of care in diabetes that were the primary focus of the Bolton project.

The idea of co-authorship took us further, seeing the progress of a person with a chronic condition as a continuing narrative, whose story-line was in some measure co-directed by the person and their medical collaborators. This emphasises that co-creation in this sense needs to be thought of not just as an exercise in 'participative planning', nor as an aspect of a medical putting out system of self-care, but rather as a dynamic concept, involving the interplay between design and experience, one that demands experimentation and adjustment. It further highlights the importance of the process of feedback and learning, and recasts the relations of self-care from one of patient education and compliance to one of mutual interpretation and adaptation.

The resonance of the idea of co-creation comes from its focus on the current core medical relationship. The Bolton project began to explore some of the conditions and tools which would help to re-form this relationship, including new elements of training and new practices on the medical side, and new sources of knowledge, support and life skills on the side of the patient. It raised questions about the nature and authorship of medical records, of their physical and linguistic accessibility and the forms of presentation of medical results, all areas which were clearly in need of a substantial helping of user-centred interaction design. It also prompted discussion about the time and continuity of care, of the potential impact of new media and communication technology, of group consultations and feedback sessions (now common in the US and increasing in the UK), as well as issues surrounding the growing demand for multiple interpretations (diagnoses) and the locus of responsibility and liability in a less certain world.

Above all it pointed to a redefinition of roles - a more informed and proactive patient-as-person on the one hand, and a medical professional in an advisory rather than an instructive role on the other. The sociologist Zygmunt Bauman has talked of a change in the role of intellectuals from that of legislators in the Enlightenment to interpreters in a post-modern world. For intellectuals here read doctors and their interpretative role in the era of self-care and the prevention of chronic disease.²⁶

The Agenda cards are no more than an initial tool in that changing relationship. The cards themselves need to evolve. There need to be different packs for different communities - a pack in Urdu for example. Each card - 'I want to give up smoking' for example - may itself spawn another pack to help chart a way forward. A nurse suggested that medical staff need their own pack, relating to the problems they have as front-line workers. A chest specialist has suggested a new pack for his patients. Another PCT enquired about developing packs for asthma and dermatology patients. These responses and the positive reaction to the cards by patients and by professionals in Bolton indicate a readiness to engage in a new relationship. They provide one of a number of entry points into the development of co-creation.

But co-creation is by no means confined to the medical relationship. Indeed the programme of activity in Kent had no connection to the NHS. It underlined the point that the medical relationship is only one of a much wider net of relations in open health, which themselves need to be taken into account in the formulation of the medical role in chronic conditions like diabetes.

Circles of care

The first of these are the micro-relationships of everyday life. In Bolton, all the people with diabetes with whom we spoke were supported by spouses, or by family and friends. They are all part of the primary unit of care and are often the most proactive on the part of the people for whom they are caring. Nationally they constitute a parallel NHS. There are an estimated six million people caring for family and friends, of whom 1.25 million provide more than 50 hours a week of care.

Shifting the locus of action in open health from medical institutions to individuals, does not mean a shift to isolated individuals, but to people with their networks of friendship and support. Yet the NHS is still structured around the individual doctor/patient relationship, and only gradually - social care, mental health and childbirth are notable examples - is the circle of care being given the recognition and support it merits in the provision of self-care. To give one example of the importance of this point, we met with an example of a man in the South Asian community whose wife was unaware that he had diabetes, yet was responsible for the preparation of all his food.

The mobs in Kent illustrate a different point. Their focus was less on self help than self-action, and they drew their strength from being formed around existing social groups and networks (rather than formally constructed organisations). The successful mobs knew each other and shared values. They were self-formed and self-managing, deciding who to include and exclude.

Open Health activities can thus be formed as an overlay to these relationships and extensions of them, much like a book group. They draw on and provide a setting for micro-collaboration, on which an open health system critically depends.²⁷ Designing for co-creation means designing to facilitate small-group collaboration of this kind.

Collaboratives

There has also appeared a wider, equally significant form of collaboration. It predates the development of distributed information and communication systems but the technological changes greatly extend its scope. There are a growing number of self-help groups, or user-led partnerships around particular conditions.

Some of these are formal organisations, charities which have lobbied for the interests of those with specific diseases, and provided support services for them. Some of them have pioneered new forms of care like the hospice movement, and developed collaborative structures like Alcoholics Anonymous. There are now 30,000 such formal and informal 'self-health' groups in the UK, 40 per cent of whom are engaged in work on prevention. The question for such groups is whether their work provides supplementary services on the model of the NHS, or whether it goes beyond this to promote inter-personal collaboration and the practices of co-creation.

Alongside this voluntary economy, the internet has opened up the possibilities of virtual health communities. The rapidly growing disease-specific websites and chat-rooms are an instance of this. But they could develop further on the model of open source collaboratives like Linux, or user-centred sites like eBay or Amazon. Such collaboratives have been most successful if they formed around a purpose, and provide ways in which members could usefully contribute, with easy-to-use tools, and yielding mutual benefits. The health collaboratives between professionals have been a successful example within the NHS, as has the lay led Expert Patient Programme, but there is great scope for expanding such networks - collaborative communities as we call them - as a means of independent information, discussion and support which the NHS itself cannot provide.

The resilience of complex systems is marked by their degrees of connectedness. Open Health will be characterised by a discontinuous expansion of collaborative relations and the repositioning of medical services to take account of and support such collaboration.

Deep support

Personal support

In a recent book, Soshana Zuboff and Jim Maxmin argue that there is an emergent trend in post-industrial capitalism, which they call the Support Economy. The complexity of post-industrial living has led to demands for specialised support and personalised packages of services that address contemporary user needs. The services include personal advice, market and service information, assistance with buying and selling in imperfect markets (like getting a plumber or buying a second-hand car), as well as help with the innumerable complexities of household management.

The provider of support is at the same time an adviser and advocate, as well as a factor and assembler of services and commodities on behalf of individuals. Critically, they are on the side of individuals. This is one of Zuboff's and Maxmin's main points. The loss of trust in the major institutions of the industrial age, and the antagonistic character of market relations, means that there is a widely felt need for support which is unequivocally on the side of the individual. The support provider has first and foremost to be trusted. They should therefore be independent of existing large private or public institutions, and of external imperatives which undermine trust. In the support economy economies of scope, of information and of trust replace economies of scale as the principal dynamics.²⁸ The growth of concierge services and of a wide array of personal advisers and coaches reflect this trend.²⁹

We found that this need for personal support has strong echoes in health. As we have seen, the need for support emerged in both test sites. Much of this support comes from a person's immediate circle and from other informal channels like the web or the growing number of self-help groups and primary care led sessions that we have discussed. But between this lay support and the professional structures, we became aware of a 'support gap' both in the self-management of diabetes and the promotion of activity. The need that emerged was for someone with specialist skills relevant to life and personal health management.³⁰

There is a new role to be played by a health support service. The service would help navigate and negotiate the complexity faced by individuals with respect to medical services and all things that bear on health. They would perform a similar function to theatre reviewers or the Good Food Guide in providing a guide to service availability, surfing relevant information, and like a mentor help chart and then support a course of action. They would act as personal advisers and advocates and might provide a specialist skill such as fitness training or cooking. The role could be played by part timers, by volunteers, or by a new type of specialist professional life coach.

They would have three characteristics of importance. First they would have access to knowledge and skills not immediately available to any individual or their informal network of support.

Second, following Zuboff and Maxmin, it is important that they are independent, and on the side of the individual, and not seen as one of the antennae of some other interest, whether that be private or the state.

Third, because of the asymmetry of knowledge, relations of trust and a measure of face-to-face contact are central.³¹ From the side of the individual we found that this would be helped if they could choose their coaches. The coaches for their part need their own version of the Hippocratic Oath.

The significance of such 'case' support is reflected in the US chronic care models of Evercare and Kaiser Permanente, with their introduction of personal support for the minority in greatest need at the top of the care pyramid. The new community matrons have been inspired by this model within the NHS. There is also the innovative proposal in Choosing Health (November 2004) to create a new category of personal health trainers, the first 12 pilots of which have recently been announced.

These developments within the NHS and the experience of the prototypes in Bolton and Kent point in the same direction. A distributed economy of informal and formal support is central to the success of an open health economy. But this support service should be provided for those at risk of chronic diseases and not just those who already suffer from them. There is a strong case for developing this service independently of the NHS, initially through social enterprises run by trainers, linked by a network for sharing experience and ideas.

The main financial cost would be the cadre of personal advisers and trainers, but this needs to be set against potential savings in the short term (fewer visits to the GP, less absence from work, reduced invalidity benefit required) and in the long-term (reduced onset of chronic disease or complications).³²

Service assembly

The two case sites also uncovered the need for a second type of support, the assembly of a package of services relevant to the particular person and condition. For people with diabetes we found that the services that would help them often lie outside the NHS. It could be access to healthier food, or to fitness facilities, or to financial or employment advice. Or it could be a number of different services, either existing or yet to be developed. There is a new support role for someone to be an assembler of personalised services on behalf of individuals. One of their prime tasks would be to identify the availability of trustworthy services, and negotiate access to them.

For example, we learnt of a Housing Association that organised a smoking cessation programme in the North East. Focusing on pregnant women (who were in close touch with the health service workers during pregnancy), it arranged with Starbucks to provide cessation clinics in their coffee shops, it negotiated cut price entry fees to health and fitness clubs, and reduced bank and insurance costs for those ceasing to smoke. It even persuaded O2 to provide free unused bandwidth to those involved in the programme. In another prototype initiated by one of our advisers, a 'financial doctor' support service was located in doctors' surgeries and discovered high levels of unmet demand.

In some cases services which are closely connected to maintaining good health could be brought together into a 'federation' or support collaborative. We could imagine a federation of the local council, a housing association, a football club, a mobile phone company, an employment agency and a retail chain offering an integrated package of low-cost well-being services, which took advantage of surplus capacity and the savings of multiple transactions normally only available to large institutional buyers. They might provide cheap access to municipal facilities and off peak public transport; to out-of-hours school facilities and off-peak hotels; they could arrange for home delivery services for shopless estates or for roads to be car free to encourage cycling at particular times.

In some cases a package of support could be supplied through a common portal - whether that be a GP surgery or a digital spine. We visited a medical practice in the West Country which is building a new health centre with space for complementary therapists, a beautician, an organic food shop and café, internet access for patients attending the surgery, spaces for meetings and peer-to-peer sessions, and a library. It gives a kite mark to local shops that sell health-supporting products and has the potential to act an incubator of new projects and activities. It points the way to a new model of primary practice in support of open health. The only question is how the practice can generate the time and capital to realise the full potential of ideas.

New forms of organisation

The National Health Service is organised on the model characteristic of the age of mass production. Funded from taxation, it has proved itself to be among the most outstanding providers of universal pathogenic care. But a distributed, co-creation approach to preventative and chronic self-care suggests a quite different organisational model to that of the current NHS.

Collaboratives

The first of these - communities of co-creation - we have already discussed. These are the collaboratives that form around particular conditions or activities - self-help groups or user-led partnerships, informal associations with little if any formal structure. There are many established forms, from sports teams, to walking groups, from 'slow food' networks to those engaged in community gardens. Some have formal structures and processes - whether they be clubs, or peer-to-peer groups like Alcoholics Anonymous or the Samaritans. But many work with no formal organisational shell.

The internet has greatly extended the range of such informal collaboratives. Chat-rooms are the contemporary version of the market square. Often they form around a purpose - as with Linux, or Wikipedia - or a topic or issue. The virtual platforms for these peer to peer communities have developed their own rules and filters. The BBC's I Can initiative (now the Action Network) found that there was a role for active hosts of virtual collaboratives of this kind - to encourage people in as much as facilitating a dialogue. We believe there is great scope for such open organisational forms in the new health economy - easy to join, easy to leave, but with the potential to lead into closer forms of collaboration, including discussions and action (as Howard Dean found in his open source campaign for the US Democratic nomination).

Active mobs were micro-collaboratives of this kind. The interesting question from an organisational point of view was about the nature of the meta-structure that would allow the mobs to form. Who would have the responsibility for the development of the platform and the tools, for negotiating the discounts and for determining the rules of engagement (could all mobs register, under what terms could they access the benefits)? The mobbers neither wanted the Council to run it, nor to themselves form an organisation, with committees and elections. You didn't have to elect a committee to go shopping, so why did you have to do so to go mobbing?

In a number of the examples we have cited above there is a structuring body - whether it be Linus Torvalds, or the BBC's Action Network Team. No one elects them, but rather they provide an offer of a means of active engagement, and the test of their success is whether people are attracted to engage. This is a mark of the collaborative economy - it depends on attraction to the idea and the experience, which explains so many of the features of open source systems. Open systems rely on free inputs that contribute to free outputs. The question then becomes under what conditions people will contribute freely.

Firstly you have to trust the organisers - hence the need for transparency. It must be easy (and free or cheap) to engage. It should have shared concepts and goals (which may be the main incentive) or people may participate for what they get out of it - information and tools for example, or peer recognition and a sense of self worth. The design of open collaboratives, as with open systems more generally, needs to revolve round the complexity of incentives and disincentives when participation is voluntary.

The organisational model then, at every level, is of initiatives that can attract participation. With markets the bottom line is net income. With collaboratives the bottom line is participation.

Social enterprises

There are many different bodies that become magnets for collaboration. Voluntary organisations formed round a particular chronic condition that have often provided services to members, have also acted as providers of platforms and support for 'communities of co-creation'. It is also possible for private firms to play this role - though to do so they have to overcome the tension between their natures as a private profit oriented enterprise and that of a voluntary economy (professional sport provides examples both of this tension and how it has been overcome).

In part to avoid this tension, there is a potentially significant role for social enterprise, structured to advance the principles of Open Health. This was the conclusion of our work in Kent. The County Council has agreed to back a social enterprise to promote active mobs throughout the county. It will develop the platforms, arrange for discounts and undertake the marketing. Its success will be measured by the number of its active participants.

Enterprises of this kind have been notably successful in developing environmental activities and fair trade, driven by social goals and subject to the requirement of commercial viability. The social purpose of these companies acts as a magnet, attracting in volunteers, ideas, customers, discounted services, and much other goodwill. Some of them have raised capital and shared ownership with the users and suppliers, but this is only one form of engagement, and, like the relationships and conduct of their operations, must reflect the principles of the enterprise and further its purposes. Just as public companies are disciplined by a financial imperative, these enterprises are subject to a social imperative.³³

We see this kind of social venturing as being particularly appropriate to the field of health. Health as a sector is governed by strong social goals and professional commitment. Open Health relies extensively on the informal ties and good will of families, friends and volunteers (there are currently 16 million unpaid carers contributing work valued at £57 billion each year). Social enterprises formed round these values provide a promising organisational structure for the production of tools, platforms and services, which are the infrastructure for the kind of collaboration that is now emerging.

The precise form of these enterprises is open. Some GPs are reconceptualising their practises as social enterprises. We were told of one who had established a patient-owned enterprise providing information. A venture could be established by a group of people with a common condition (we met with an example in diabetes), or specialist skills (like a life coach). Our projects threw up a number of potential venture opportunities, aside from Activmobs and life coaches. They included the development of Agenda cards, of the health miles smart card, an integrated service of diabetes support (and service assembling more generally), and a range of services linked to chronic disease and employment. The general point is that there are numerous opportunities opening up suited to social venturing, that can facilitate the informal collaboration on which Open Health depends.

Federations of support

One particular area for organisational innovation we have called federations of support. These are collaboratives of service providers, with a lead assembler, that supply personalised packages of support. They are founded on a double principle of trust and economy.

Collaborative federations of this kind are being formed by local councils. On one housing estate in London, we found a concierge service was already playing this federating role. A number of housing associations and tenants management committees are also interested in organising a multi-faceted support package on behalf of their tenants. We have seen the potential for GPs to play this role. The point is that a health support economy needs someone to play the cross cutting organising function on behalf of individuals, whether it is a public body, a social enterprise, a community group or a network of personal support workers.

The participants in the federation will also be varied, and will include private companies. But the principle of the federation is that whatever the interests of the members of the federation, they should operate in accordance with the principle and rules of the support economy. The Federation serves as a form of brand of good practice. It will help if it is led by a trusted organisation, one with recognised social goals, which acts as a quasi-guarantee of the conduct of the federators. As with the GPs, the federators could come from within the NHS, or local public services. But if they are to succeed they should be given substantial autonomy in what services are assembled and who provides them. Their success will be judged by individual response.

Designing for Open Health

We have identified four principles or logics that distinguish an Open Health system, and suggested how these differ from the traditional medical model - in system architecture, professional and social relationships, in forms of support and organisational structures. There are notable contrasts with respect to processes of research and innovation, to metrics and financial accounting, to the mechanisms for distributing information and financial resources, and for the whole economy of motivation and incentives. These differences are summarised in the table overleaf.

In choosing the term Open Health to describe the emerging system, we have intentionally emphasised those characteristics that the new technological era has made possible. For the new systems have not only transformed the economy of information, opening up the terms of the dialogue between medical professional and patient, they have created an infrastructure for lateral conversations and activity. In doing so they have brought about the conditions that enable the design principles with which we started out to be realised - distributed resources, collaboration and co-creation.

In taking further our understanding of the design issues in these new systems, we found ourselves in quite different territory to that addressed by the industrial models of flexible manufacturing which have inspired the current reforms of pathogenic healthcare. The latter are concerned with service flows and transactions, and with issues of complexity in the production of these services. Open health starts not from services (however personalised) but from individuals, and the relationships, knowledge, and support which are necessary for them to be active agents of their own health. It is less Toyota, than the models emerging from the dot.com economy which appear most relevant, together with those of the informal economy, with its emphasis on reciprocity, trust and values, on the other.

We thus also became aware of parallel contrasts in health system design, a contrast between designing for a sequential service and designing for open ended systems. In a delivery service based on treating people's needs, the emphasis for design has been on how to achieve accuracy, efficiency, performance, safety and ergonomics. As the system struggles to become more 'patient friendly', design is applied to increase access, improve navigation, streamline the 'patient journey' and improve the emotional experience of linear healthcare.

In the Open Health model on the other hand, which is essentially about choosing to live one's life in a different way, the scope of design has to be extended. It has to take on board motivation, distributed information and multiple types of feedback. It has to design settings for relationships and tools to support them. Overall it has to make any system compelling, aspirational, and easy to use. It must appeal to every individual as the desirable option. Designing for Open Health is designing for desire.

| Medical | Well-being |
|---|---|
| Disease | Individual |
| Service | Platforms |
| Transactions | Interactions |
| Passive consumer | Active producer |
| Object | Subject/Agent |
| Fixed and standard code of treatment | Diverse, personal and evolving |
| Knowledge concentrated with medical professionals | Distributed information on experience and strategies |
| Treatment | Motivation |
| Professional monitoring | Co-created monitoring & feedback |
| Slow, high cost innovation | Distributed, continuous innovation |
| Delivery through medical professionals | Deep support/peer to peer/ pro-ams/volunteers/with professionals |
| Centralised complexity/high overheads | Distributed complexity/low overheads |
| NHS | Communities of Co-creation/ Social enterprise/Service Federations |
| Flow line treatments | Multi-faceted activities |
| Burdened by demand | Strengthened by participation |
| Gatekeepers | Open access |
| Activity based accounting | Person centred accounting |
| Centralised finance and accountability | Distributed control of resources/ health currencies |

Designing an open model

The creation of healthy lifestyles is not so much about designing a service to be delivered but designing for a public good to emerge. For that to happen the conditions must be right, and the motivation and opportunity must be aligned. For the design industry this is relatively uncharted territory. In contrast to the sequential delivery model, we can't fully design a 'good health' system. But we can design the elements, or the conditions that enable new behaviour patterns to emerge.

We can view the context for a potential system as a landscape of current behaviours, interests, opportunities and resources. These elements exist already, but have not been drawn together in a way that constitutes a mutually beneficial framework. The potential is there for new value to emerge if those elements are connected in a particular way.

We have identified six points of focus for design in these emergent systems:

- Platforms
- Tools
- Touchpoints
- Rules
- Support
- Prototypes

Platforms

In our work we have been continually drawn back to the idea of a 'platform'. We use this to refer to a common 'arena' or 'framework' that allows shared use. Platforms can be websites, programming languages, networks of people or structures. In computer science a platform is an operating system formed by hardware and software. In some industries a platform is defined as a set of shared protocols or components. In other organisations it may be a shared set of principles.

Platforms are often modular in their architecture. Their rules may be published or simply be understood. They are generally not location based or geographically determined to allow maximum access. Essentially a platform is a shared structure upon which a number of other things can operate and collaboration can take place.

Platforms need to be designed in such a way as to **attract** support and participation, and **distribute** access to tools and resources.

Rules

To work well, platforms need a set of shared rules. These may be explicitly stated or documented, or they may be implicitly understood and accepted (as with social etiquette). It is these more informal, 'social' rules that become more prominent in systems that require the participation of a community or members.

The founding partners of livework discovered this during their work with Fiat exploring car sharing services. As car sharing communities formed, they each developed a set of specific rules – about keeping their shared cars clean, for example. People could only remain a member of one community if they adhered to that particular set of rules. Those breaking the 'rules' are quickly ostracised from many open systems. This has given rise to a spate of new tools to allow the filtering and modifying of participation.

Sets of rules within a given context, may form a platform in their own right, perhaps in the way that in a card game the tools are the cards, and the platform is a set of understood rules – kings are high, hearts form a suit – from which many derivative games, each with their own sets of rules, can be devised.

Tools

The term 'tools' is used to refer to the things that help people to make use of the system. Tools enable people to access the platform and create or extract benefit from it. They facilitate participation and collaboration. In open systems they are distributed, giving greater autonomy to participants.

Tools might be gadgets (e.g. pedometers, blood glucose meters), software (e.g. friend of a friend software, search engines), mobile phone applications, web tools, templates or how-to guides. They may be custom designed products, like the cards in the Bolton project and the 'suggest-a-mob' tool in the Kent project. They may exist simply to help people to navigate the choices on offer.

The distribution of tools is key to the success and reach of the system. They must be easily accessible and useable to all to ensure maximum participation. The use of web-based tools is a natural solution to breadth of distribution. However, internet use is not feasible for everyone. In our projects we also used low tech tools, such as the Activmob catalogue to ensure that a number of access opportunities were provided to suit all means and abilities.

In the same way that open source code allows people to create their own derivatives, tools should support and enable people to create versions of the system offering that best suits them – e.g. an activity group based around their own interests, social networks and timeframe, or a personal agenda for tackling the management of diabetes.

Support

We have argued that Open Health requires multiple and complex forms of support, which need to be addressed by design. Support roles within these systems are multiple. They appear in response to demand and can be fulfilled by amateurs or professionals, making use of previously untapped resources. Motivators are amateur roles in the Activmob system, for example, and professional support comes in the form of personal trainers. One person may play many different roles within the system over time.

In many open systems the formation of roles is organic – people are attracted to a responsibility that interests them rather than having responsibility placed upon them. Many are about making use of existing social skills as well as professional expertise – roles for people who are natural organisers or motivators, for example.

Participation depends on a combination of interest, opportunity and motivation. Therefore the elements outlined above must be carefully designed to facilitate this by sparking interest, presenting opportunities and creating motivation. This must be done in multiple ways to appeal to many individuals.

Touchpoints

The system is accessed through a series of 'touchpoints'. In service design, touchpoints refer to points at which a person comes into contact and interacts with a service or system. Typical touchpoints include websites, built environments, waiting rooms, phone lines to help desks, proprietary products like credit cards, interactions with employees, letters and billing statements.

The design of these touchpoints is crucial to the success of the system. They will either turn people off or engage them further. Even the tone of a voice on an automated phone line must be designed to reinforce the ethos of the system. In systems that depend so much on the successful engagement of participants, thoughtful design of touchpoints is imperative.

Prototyping

Prototyping these complex services or systems requires a different approach to that of prototyping sequential services. Many decisions must be taken simultaneously, and changes often cannot be isolated, having an unpredictable effect on the ecology of the service. One cannot start at the beginning and work forwards from there.

We found the best approach to be to construct enough of the above elements to test something out quickly and cheaply – a kind of bricolage approach - and to grow the concept outwards from that central interaction. Designing tends to be a mixture of pragmatism and intuition. With open-ended systems the outcomes and effects of one intervention are not easy to analyse. One cannot apply an intuitive approach to testing out surgical operations, but it is equally difficult to apply a more Fordist approach to personal systems and lifestyles.

To test out experiences, reactions and behaviours, designers have begun to employ techniques such as Experience Prototyping³⁴ – staging a particular experience rather than setting up and testing out the service. In contrast to a controlled user test – say of navigation through a pre-designed website - this is itself an open-ended approach. Certain elements, props or instructions are given to participants, and the experience is left to unfold. Responses are unpredictable and can lead the project in new directions. The staging elements can be quickly adjusted to test out that new direction. We found this method particularly useful in determining how Mobs needed to be supported and motivated, and in understanding how they might react to new members joining.

Systems like Open Health depend on co-creation between participants and professionals and the nature of those relationships shapes the way the system develops. The role of the designer changes significantly in this context. The designer's task is not to communicate function, control form and determine the experience, but rather to inspire participation, enable possibilities and support relationships.³⁵

The climate of health

Problems of transition

The kinds of changes implied by a shift from a flow-line process of pathogenic care to an Open Health system are notoriously difficult to bring about where the organisation and financing of the service are the responsibility of the state. The great innovators of industrial production, from Arkwright, to Carnegie, Henry Ford, Bill Gates and Steve Jobs were able to challenge traditional systems of production through the market. It is much more difficult to open up such autonomous spaces for system innovation with the centralisation of control of a public (or a monopoly private) service. Innovation in these cases tends to appear at the margins - in places where the institutions of the old order are weak.

Many of the industries facing the challenge of change in the current era of the information and communications revolution - from public transport, to energy, water, waste, and education quite apart from health - are controlled by centralised public and private institutional structures of this sort. One response has been to open them up to market competition - and this has been a feature of the recent NHS reforms. But in all such services there are problems in using the mechanisms of a private market economy - which is why they have been made public in the first place. The broader policy issue for public sector reform is whether it is possible to produce the kind of 'open' structure for innovation provided by the market in industries that remain within the social or public sphere.

In the case of health, this may be easier than in some other fields. For a system of Open Health is not replacing the pathogenic system - hospitals, GPs, and chemists are still all necessary but reduced. Rather it is growing up alongside it - in its own household-centred operational space - and now has a wide coalition of support because of the gathering crisis of chronic disease within the NHS. There is not the head-to-head conflict as there was when the horse drawn carriage faced the motor car.

Yet to say it is easier, can only be relative. There is still a major imbalance of resources. There is a tendency to reproduce the centralised structures of the NHS for the organisation of public health. Policy models are still couched in terms of instruction rather than of motivation and of service package delivery rather than platforms. The old has difficulty in playing the midwife to the new.

Just as Open Health involves a new concept of a public service system, so there needs to be a new model of policy to develop such a system. If today public health and self-care remain in the shadow of the hospital, what can be done to bring them into the light?

Problems of Open Health and self-care are seen as diffuse and intangible. This places a particular onus on Government. Choosing Health and its subsequent delivery plans represent a remarkable step forward in trying to integrate the many facets of public health. The Treasury in the UK (as in the US) has developed a keen interest in effective policy because of the budgetary implications of the time bomb of chronic disease. Yet the political task is to find ways to bring public health and the self-management of chronic disease out of the shadow of the hospital, and into the centre of political debate.

Among the innovations needed are:

1. New economic instruments

The application of producer responsibility to health would mean identifying those products or industries that unambiguously contribute to ill health, and requiring their producers and distributors to fund the costs of the treatment resulting, or provide countervailing services. For example:

- The motor industry could be required to fund a target mileage of separated cycle track or pavement restoration (in both cases it would encourage local authorities to submit schemes to an industry run challenge fund process).
- Cigarette companies could be required to fund smoking cessation programmes with reduction targets attached (the principle of getting industries to manage reduction of demand for their own product is found in the Energy Efficiency Commitment which sets targets to power companies to reduce domestic gas and electricity consumption).
- Junk food companies could be given targets for the supply of free fruit and fresh vegetables for all schoolchildren, and sugar companies for the provision of personal fitness trainers (a number of US states are considering special taxes on soda and snack foods).
- A 10 per cent levy could be put on all food and alcohol advertising to fund healthy food and drink campaigns; the same principle could be applied to motor vehicle advertising to fund campaigns for walking and cycling.
- The media revenues of professional sports association should be top sliced for clubs to provide sports promotion and community programmes (the responsibility here is for professional sport to fund training, facilities and promotion to the informal sport economy which acts as the social reservoir of talent on which professional sport depends).

The point in all these cases is to not just to extend the concept of property to cover liability for the effects of what is produced (caveat emptor should no longer be a defence), but encourage innovation within the producing sectors themselves. A number of major food companies have said they wish to be part of the solution and not just part of the problem, and the form of the responsibility should provide an incentive for restructuring of this kind.

In the above cases, following the growing practice in the environmental field, certificates of compliance would be issued, and those companies exceeding their target could sell their certificates to those who have failed to meet them (with the government acting as compliance issuer of last resort).

Consumers, for their part, would take their share of responsibility not through the payment for healthcare (since the link between lifestyle and ill health is one that holds at the population rather than the individual level) but through the increased prices of those goods and services covered under the producer responsibility obligations.

The above measures contribute in part to the internalisation of costs of certain types of consumption. There is also the question of the capturing the benefits. For example individuals participating in collaborative travel plans could benefit from lower insurance costs. With a health miles card, those participating in screening programmes would be credited with points. Firms providing personal health trainers for their employees could have rebates on their national insurance contributions, as could those employing people previously on incapacity benefit and providing work-based support services for them.

Economic instruments of this kind can also be applied to local authorities as a means of them accepting their responsibility. To take only one example, tradable permits are being introduced for the performance of statutory local authority services, such as the disposal of waste to landfills. Those local authorities exceeding their landfill reduction targets are able to sell their surpluses to deficit authorities. A similar mechanism could be introduced for local authority provision of the infrastructure of Open Health, as a complement to producer responsibility obligations (such as swimming pools, sports fields, footpaths and cycle tracks, those key facilities and services which are currently not a statutory requirement on local authorities to provide).

2. Hypothecated taxes

The controversy in the 2005 election over the modest increases in national insurance contributions to fund increases in health expenditure are likely to be dwarfed by the increases in health costs estimated by Wanless. Expenditure on public health, already marginal in relation to the NHS budget, is particularly vulnerable to crowding out by increases in the costs of acute care and by cuts in public sector budgets. Inadequate finance is the greatest threat to the ambitious programme outlined in Choosing Health and to spending on improved chronic care self management.

A primary task is to secure ring-fenced finance for a sustainable and expanded programme of long-term investment in public health. This means dealing with the issue of tax. The central problem with taxation is that it has lost its legitimacy, because of the lack of connection between tax raising and spending. The centralised public budgetary process - which took more than a century to establish in Britain after the late 18th century reforms - obscures these connections and leaves the process of allocation subject to closed interdepartmental bargaining at every level of government.

The problem of taxation is a problem of design. A designer would start from the user, in this case, the payer of taxes, and ask how can a tax be designed that would be readily paid? The answer centres round the tangibility and desirability of what the money is spent on. It depends on the connection between revenue raising and a collective service, and on the degree of consent it commands.

One way of re-establishing that connection is through hypothecated taxes. Their transparency means that they are the very opposite of stealth taxes. The case for them has to be argued on the basis of the specific services funded. They are a way of re-legitimising public finance.

The funding of public health should be established on this basis. As with the BBC licence fee, the use of the funds would have to be such that there was continuing public support for the continuation of the levies. Just as the Climate Change Levy on non renewable energy used by firms is now accepted and is used to finance CO2 reduction measures in business, so an Open Health levy should fund a continuing programme of public health.

There are three design issues, the programme to be funded, the incidence of the levy, and the connection between the two. On the first, Choosing Health and its subsequent delivery strategies has already provided a formidable menu: wholesome school meals, accessible playing fields, separated cycle tracks, improved pavements and street lighting, walking websites, community gardens, an extended Expert Patient programme, personal health trainers, new screening programmes, fresh fruit vouchers or food box schemes - all within the context of the epidemic of chronic disease. Such a programme is more tangible and more difficult to oppose than a generalised penny on income tax.

But what of the levy? Its incidence should have a narrative link to the spending. The examples

given for producer responsibility instruments illustrate one kind of connection. Those generating a cause of ill health should fund the resultant costs or remedial measures. Other sources of levy to consider are:

- A 50 per cent share in stamp duty for the funding of local Open Health facilities, as a form of entry fee to collective facilities for new residents in an area.
- Twenty per cent of business rates being earmarked for Open Health programmes, on the grounds of collective gains for employers from an improvement in a community's health.
- 10 per cent tithe on patented drugs, since the principle of patents is to fund future pharmaceutical research, and a proportion of these funds should now be diverted to prevention (this could be translated into a form of producer responsibility, in the sense that pharmaceutical companies should share some responsibility for the prevention and not just the cure of ill health)
- A 10 per cent share of tobacco and alcohol taxes
- The proceeds of VAT on sodas, snacks and high fat foods

3. An Open Health Trust

Another of the innovations in environmental policy is the establishment of separate arms-length social enterprises to focus on the delivery of outcomes. Their boards are formally appointed by Government, and much of their finance comes from government, but their corporate form, their institutional culture, and rules of operation are independent. They operate less as agencies, than as enterprises with a public purpose.

The principle underlying them is that preventative approaches (to energy and waste) need new institutions, and that the corporate form (whether as a trust or company limited by guarantee) provides greater scope for innovation and the establishment of an institutional culture approach to the new direction.

A similar point applies to public health. Our argument has been that Open Health involves a quite different approach to traditional curative medicine. Those working on public health and self-care within the existing health service, whether in the Department of Health itself, the senior management of the NHS, or in the front-line as doctors and nurses, are trying to develop this new approach within the structure and culture of the old. We have referred to this as a tension, and it is evident in health education, in the criteria for action, in much chronic care management, in patient involvement, and in such new initiatives as the health trainers programme.

What marks these all out is that they start from the system and its recommended practices rather than the individual. It is about system-led procedures (the 'oughts') and then compliance with the 'oughts'. It is still at its core a mass service model.

We have argued that for full engagement as outlined by Wanless, this model is not appropriate. We need an open system in which the centre (in this case the NHS) has to let go. It is not an abandonment of responsibility or accountability, but rather of finding different forms of influence in the ways we have suggested - through norms and systems of incentives, through the provision of advice and services, through the design of platforms and tools. But control is now diffused, or as the lawyers say, pulverised.

It is for this reason that we recommend the establishment of an Open health Trust. Its brief would be the promotion of Open Health. It would be the animator of the new system. Its core funds would be from hypothecated taxes of the kind outlined above, matched for projects by other private, charitable and public finance.

4. An Open Health Investment Fund

As a complement to the Trust, and again inspired by the experience of environmental sectors, we recommend the establishment of a specialist Open Health Investment Fund, whose prime purpose would be the promotion and funding of social and other small and medium enterprises (SMEs) in the field of Open Health.

Over the past 20 years there has been a significant growth of a financial infrastructure to support the development of SMEs. But in sectors where the primary markets are in the public sector (as would still predominantly be the case with Open Health) small firms, and in particular social enterprises, have found it difficult to attract funds from the traditional banking network, partly because of a low fixed asset base in service organisations, and partly because short-term public sector contracts are not seen as a bankable proposition. From their side, the public sector contractee is unwilling to take the performance risk with small, local enterprises. Grant funding rather than investment finance has characterised many parts of the social enterprise sector, with growth financed by reinvested earnings.

In the development of Open Health we think there is a role for a fund based on the model of social venture capital and development banking. It would provide capital in the form of equity, preference shares, unsecured loans, and (for some activities) grants, and would also act as a guarantor for the financial and performance package offered to clients. We would expect it to leverage other funds, not least from investors attracted by the goals of the enterprises rather than their profitability.

Initially it would be established nationally, with equity advanced by the Open Health Trust, but would then form local funds, aiming to attract onto their boards leading entrepreneurs and specialists, and to establish venture federations/partnerships with other local players. Like mainstream venture capital, its technical advice and support would be as important as the finance, and it would seek to connect new enterprises to a network of reliable and high-quality technical services.³⁹

5. A new person centred metrics

Environmental impact techniques such as life-cycle analysis allow firms and policy makers to trace the impact of alternative products and processes on a wide range of environmental variables. It is also possible to track the financial savings of investments in, say, domestic water reduction programmes as against the costs of building a new reservoir. This is much more difficult in Open Health.

There are no readily available metrics which would allow the NHS, the Treasury or local government to assess the returns on investments in public health - a point underlined by Wanless. Nor even to assess the downstream cost savings for the health service (let alone public finances more generally) of such investments. In Bolton we found that that there was no way of finding out the overall cost of diabetes care in the Borough, let alone the costs attached to each individual with diabetes, since NHS accounting is not organised in this way.³⁶ In other words, current health financing does not allow for adequate centralised economic decisions on public health and self-care, let alone a mechanism for distributed resource allocation.

The problem is finding a way of connecting investment made in a particular population with its health outcomes, and minimally with its impact on other health and public service costs. Particular studies have sought to do this, but there are no generalised data that connects those benefiting from a particular investment with their health outcomes and costs.³⁷

The Scottish Health Collaborative has recently developed a person centred community health index, which aggregates individual health records across a region to assess the impact of health policies. It has also been used specifically to track impacts on people with diabetes. There are also systems now in place in parts of the USA which integrate patient-centred clinical data for chronic diseases with person-centred accounting. This permits low-cost financial monitoring and assessment of clinical innovation, and has also had striking results in terms of mortality, chronic disease management as well as costs, and greatly extends the informational basis for the co-design and co-management of regimes of self-care. In the terms of this book, it is an important tool for feed-back and co-creation.³⁸

The US example suggests that what is needed is not just person-centred accounting, but a standard health data system, organised around individuals. For those with medical conditions, this would include clinical data, but an integrated data set could also be used for purposes of quality control of services (by comparing an individual with the aggregated data from a population), for teaching and learning, for administration and then also for costing.

The US experience provides one further lesson. It is that the systems have to be developed from the bottom up as well as the top down. Their effectiveness depends on their being designed round the multifaceted needs of physicians and on the quality of the data inputs (principally done by nurses who require training). In other words they need to be co-created with those who are to use them. They need to reflect the principles of user-centred design.

6. A Design for Health Academy

Just as eco-design has become central to the new environmentalism - designing products and processes in a way that reduces waste and hazards and embodies sustainable resource use, so we have argued that 'salutogenic' design is central to a new Open Health system. This is first and foremost because it starts with individuals, with their circumstances, their motivations, and their feelings. This we see as the starting point not only for the design of platforms, tools and services, but as we have seen in this chapter for other aspects of system architecture from finance and taxation to data systems.

As the then Director of Innovation and Knowledge at the NHS Modernisation Agency recently put it, design is the fast-growing big idea in the field of service improvement and organisational development. She writes "User-based design should become a core NHS principle - recognising patients, carers and families as producers and participants rather than just service users".³⁹ But, as yet, design has played little role in healthcare, and although there is a growing interest in service design, few designers have engaged with active health issues.

In other experiences of industrial transition, a critical role has been played by institutions that help develop the new professional skills required by the emerging system. This may be training colleges, institutes or universities, or programmes of on-site learning as in traditional apprenticeship schemes. These institutions also play a role as industry catalysts, as sources of new ideas and reflexive platforms for problem solving.

We think there is a role for a new institution of this sort focussing on the application of design to healthcare, and in particular to the development of a new Open Health system. It would be complementary to the recently established NHS Institute, which is primarily oriented to innovation within the NHS. Its functions would be four fold:

- To provide design for health courses and modules for the NHS and others engaged in areas relevant to Open Health, on the one hand, and for designers and design course teachers on the other
- to act as a hub for the development of the principles and practice of a new open health system
- To develop the demand for design in healthcare, and the availability of supply
- To promote and seed fund the initial development of Open Health innovations

The Academy would be linked to the Open Health Trust and the Investment Fund, but would have its own board of directors.

Each of the above should be mutually re-enforcing. They would contribute to providing a unifying identity to the diverse elements of Open Health, and in doing so raise its public and political profile. The introduction of producer responsibility and hypothecated finance would make these connections tangible. Even more important, they would provide the funding to radically increase the provision of infrastructure and support services, with a metrics that would synthesise individual experience of improvement into a general measure of advance. We thus see this package as embodying four of the core principles of systems policy design - user-centredness, tangibility, conceptual integrity and synthesis - all of them necessary not just for the effectiveness of the new system but for achieving long-term public support.

Open transitions

The development of an Open Health system cannot be planned in packages which are then rolled out in the form of a mass delivery model. It will have to be co-created, drawing on multiple initiatives, and generating new infrastructures and organisational structures. It is a question of creating an economy.

Currently the market for co-created health is rudimentary, as is the supply of designers of 'well-being' systems. There is a lack of information necessary to generate and finance a co-creating health economy, let alone adequate funding channels.

Yet the potential is there. On the demand side, there are a wide range of organisations with an interest in preventative health; different parts of the existing health system; local authorities; insurance companies; employers; and people/chronic disease sufferers themselves. There are few dissenting voices at the policy level, that well-being and self-care are central priorities in the UK. The Government's public health policies will themselves inject resources into the system and open the way for innovation both from within and outside the current medical system.

From the side of supply there are the potential platforms, and services necessary for effective systems of co-created health but they need extending and wiring together. We are at an open phase in the response to new needs. New institutional forms have yet to emerge, and interests harden. Existing services are open to the possibilities - mobile phone companies, those supplying the components of a digital spine, TV channels, the insurance industry, credit card suppliers, new deal property companies, pharmacists, food box schemes, supermarkets, leisure centres, highways departments, housing associations, post offices, schools, complementary practitioners, and of course GPs, and the NHS itself. This is the moment to explore the potential that each offers to the development of the infrastructure of an Open Health system and elements of its management.

The same applies to people. There is an extraordinary wealth of existing self-help groups and volunteers as well as many existing voluntary organisations concerned with chronic disease. They are primarily engaged in advocacy and support for those with particular diseases, as well as promoting various aspects of positive health. Many supply services directly - such as hospices for the dying, or care services for the mentally ill. There is great scope for these organisations to extend their range of services and diversify into social enterprises. We expect third sector organisations of this type to be central to the supply of support and other services in an Open Health economy, in collaboration with new skills and roles in primary care itself.

But how can these disparate elements be connected by the designers and generators of these tools/platforms/services where they do not exist? We believe this is a question not of introducing the new system architecture overnight, but embarking on a period of prototyping and venturing.

As we have argued, we think there is an important role that design can play in co-creating the conditions for the emergence of effective demand and supply. But as yet there are few design specialists in this field and an early task is to expand this particular component of supply.

The immediate tasks for this transitional period include the following:

First there must be a learning network, both for those on the demand side of the economy, and for those on the side of supply. It would have the following elements:

- 1- A range of learning modules, and discussion sites
- 2- A programme of conceptual development, which plays a reflective function for those engaged in system development.
- 3- An open source blog to provide information and feedback on the emergent systems.

This could provide the basis for the development of the Design for Health Academy discussed in chapter XIII section 6.

Second, there needs to be a prototyping and development strategy for new agents of the system. Some of these could be within or linked to the current NHS - GP surgeries for example, or cottage hospitals, or pharmacies. Others might have few current links with the NHS, but could play a pivotal role in a well-being economy - such as housing associations, intermediate labour market organisations, churches, retailers, sports clubs, TV stations, concierge services or banks. What scope is there for such bodies to act as federators of the new service packages?

Third, a new information and communication infrastructure is required for the self-acting patients and citizen. In some areas this may be broadband, in others and for some groups a mobile network, or in towns like Bolton where internet penetration is low, there is scope for digital TV to be the medium for new interactive services.

Fourth, there is the need for a system of resource allocation, which is not dependent on large-scale commissioning by existing health service providers. Commissioning may play a part - particularly with the move to practice-based commissioning. But on what basis would such commissioning take place with systems of preventative health? How could cause (an economic input) be traced to effect (the impact on an individual's health) or to the reduction of costs otherwise incurred by the NHS? It may be possible to make these connections at a macro-level, but as we have argued a distributed economy requires micro-measures, and micro-methods of resource allocation.

Fifth, and until such allocation systems are in place, there should be resources to fund initial projects in order to demonstrate in practice the effectiveness of the new system and thereby create a market. The resources could be provided through a challenge fund or a pilot social venture fund which would take an equity stake in new projects.

Last, there needs to be one or more bodies to play the role of hub, incubator, funder and animator of the new economy. Their task would be to promote demand as well as supply, to encourage new independent projects, to set in place the platforms that can generate platforms, and tools that contribute to the development of tools. Together these would make up a transitional programme for Open Health.

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Notes

¹ In the five years between 1997 and 2002, hospital admissions rose by nearly a quarter and the average annual number of patient visits to a GP rose from four to five.

² Rankin (2005). Since the 1980s development of mood-controlling drugs has allowed for a substantial reduction in the number of mental hospital-based long-term care beds. The pharmaceutical industry estimates that 70% of the reduction in demand for hospital beds by the end of the century as the result of the development of drugs was accounted for by mood controlling drugs (*ABPI Facts and Statistics from the Pharmaceutical Industry 2005*). But for the most part this allowed for a shift of the problem out of the hospital rather than for its resolution.

³ This is one of the principal themes of the Primary Care White Paper, *Our Health, Our Care, Our Say: a New Direction for Community Services*, Department of Health, 2006.

⁴ The lead in this has been taken by the NHS Modernisation Agency. For example they applied the 'process flow' principles of manufacturing to the question of waiting time and bed availability, and showed that the problem is not capacity as such but variations in demand and capacity and the mismatch between them. On the basis of the experience of pilots they estimate that simply synchronising admissions and discharges would release 13 per cent of bed spaces. Improving patient flow by removing bottlenecks would free up 15-20 per cent of hospital capacity. Reorganising patient queues would reduce waiting times by 50 per cent. They argue that the application of the principles of just-in-time and what industrial economists call 'multi product flow' carries with it the promise of "no wait hospitals and a no wait NHS". See NHS Modernisation Agency (2004b). See also Silvester et al (2004). Three of the authors of this article worked for the NHS Modernisation Agency. On the principles of flow see Best (1990).

⁵ This is most explicit in the Lean Health Care Forum, established as part of the Lean Enterprise Academy. See the papers from the January 2006 Forum meeting on www.leanuk.org, where Toyota lean principles are applied to such issues as bed configuration, theatre scheduling, diagnostics and laboratory organisation, and information systems with striking results.

⁶ Department of Health (2004b).

⁷ Wanless (2004) p.38.

⁸ Department of Health (2004b) p.77. The other two are fair and prompt access to services and a consumer focused maximisation of information, choice and user/carer experience.

⁹ Cottam and Leadbeater (2004).

¹⁰ For a valuable introduction to design practice see Kelly (2001). Tom Kelly is the MD of IDEO, one of the leading international design practices, with headquarters in Silicon Valley.

¹¹ Bolton is an excellent example of the best of the new NHS: a clearly articulated care plan (through the National Service Framework), joined up services for a disease which calls for a range of preventative, primary and secondary care; a remarkably committed staff (including a lead GP) who have consistently put outcomes before institutions, and which is led by one of the most innovative diabetologists in the country.

¹² Mortality rates from coronary heart disease are up to five times higher for people with diabetes, and the risk of strokes is three times higher. The disease is the leading cause of blindness in people of working age, the largest cause of end stage renal failure, and apart from accidents the principal cause of lower limb amputation. Department of Health (2002) p.10.

¹³ Department of Health (2003).

¹⁴ The National Service Framework (NSF) for Diabetes breaks down the above issues into 12 categories and sets a standard and a delivery strategy for each. It is regarded as the strongest of the NSFs developed to date.

¹⁵ The current rate is 3.4 per cent of the population as a whole. The Bolton Health Survey conducted in 2001 found that 5.6 per cent of those over 18 reported they had diabetes, with rates in one ward rising to 12 per cent, and among men over 65 to 17 per cent for the town as a whole.

¹⁶ Bolton has a substantial Asian community, who comprise 9 per cent of the population.

¹⁷ National Audit Office 2001

¹⁸ Department of Health (2003), chapter 5. See also House of Commons Health Select Committee (2004), p.126.

¹⁹ Palmer (2003).

²⁰ Gilroy (2004a and 2004b).

²¹ Hospital overheads of one chief executive we talked to approached 50 per cent of total costs.

²² We visited one GP which had been required to produce two large volumes of procedures in the practice as laid down by the Department of Health. This is reminiscent of mass production factories before the transformation of the Toyota system which turned Taylor's monopoly of work design and information on its head.

²³ On open source and open information systems see Mulgan and Steinberg (2005).

²⁴ There is a growing literature on the applicability of complexity theory to human systems and public policy, see for example Luhmann (1985), and Chapman (2002).

²⁵ There is a recent collection of papers by doctors, nurses, specialist consultants and medical researchers that illustrate how such models can be applied within the NHS. See Kernick (ed) (2004). The collection contains an exposition of concepts as well as a number of cases (with striking outcomes) of professional-led initiatives to promote open health inspired by complexity theory. There is a chapter on co-creation (p.191-204), in this case co-creation between professionals in the reform of clinical governance, which includes a mention of what are in effect learning mobs for professionals in primary care (p.197). The perspective, however, remains that of the NHS, and the papers highlight the tension between managerial healthcare and the open systems appropriate to open health.

²⁶ This distinction is made in the Shifting Perspectives Model of Chronic Illness derived from a metasynthesis of 292 qualitative research studies. It suggests that instead of a linear trajectory in the progression of chronic illness there is a continually shifting process between illness-in-the-foreground and wellness-in-the-foreground. For wellness to be in the foreground the self not the diseased body becomes the source of identity, and in achieving this and gaining control over the disease, people have been helped by learning as much as they can about the disease, identifying the body's unique patterns of response, developing their own skills, creating supportive environments, and sharing knowledge of the disease with others. The new health information economy clearly supports this process. See Paterson (2001) reprinted in Clarke et al (2004).

²⁷ Marriott (2004).

²⁸ One of the main themes of the White Paper on Community Services (Department of Health 2006) is improved and distributed access to primary care services, and provides a number of examples of Telecare, see p.119. It is much less strong on autonomous collaboration and how to support it.

²⁹ Bauman (1987).

³⁰ Mobs exhibit some of the same features of the micro inter-relations and mutual influence analysed by biologists in terms of swarming. See Johnson (2001), dealing with self managed change in adaptive systems.

³¹ Zuboff and Maxmin (2002)

³² The concierge service 10UK now has 85,000 clients, and a network of over 3,000 suppliers. Its central focus is on gaining and preserving trust.

³³ To some extent this form of personal support exists within the health service in the form of district nurses and health visitors, and has been shown to be effective for many aspects of preventative health. See the Choosing Health Briefings produced by the Health Development Agency, notably Briefing 1 and Briefing 3 (2004).

³⁴ The public desire for sustained personal relationships runs across many public services, whether in the form of a teacher, a bobby on the beat, or personal care worker. Virtual support may be part of the package, but as a supplement to personal support.

³⁵ The Government has earmarked a budget of £79 million over three years for health trainers, but this will meet only a fraction of what is required for full engagement. In Kent we worked within a target budget of £100 per person, which is 8 per cent of the average annual per capita cost of the NHS. For the diabetes coach, with more one-to-one contact, the initial figure was higher, but still offered potential savings if it postponed the onset of complications.

³⁶ There has also been a striking growth of such companies in the leisure sector, managing swimming pools and leisure centres for example.

³⁷ Experience prototype is any kind of representation, in any medium, that is designed to help us understand, explore or communicate what it feels like to engage with a product, space service or system. Traditional design prototyping tools like storyboards, scenarios, sketches, models, video, or on-screen simulations are able to communicate the elements that make up an experience and do this by inviting people to look-on rather than actually participate. Experience prototyping would involve activities such as role-playing, simulation sessions, (using appropriate props), and analogous situations that are carefully-designed/or selected to highlight particular qualitative aspects of engagement with product, space, service or system. Buchenau and Fulton Suri (2000).

³⁸ Chris Downs and Ben Reason, live|work, from a presentation at Doors of Perception 8, New Delhi, March 2005

³⁹ The Government announcement of plans to establish a social enterprise fund to provide support for third sector suppliers by April 2007 is a welcome move in this direction, but it needs to be a source of investment finance and not just a provider of advice and initial grant funding. See Department of Health (2006) p.176.

⁴⁰ Payment by results is likely to yield some improvements in this kind of data - where particular procedures like an amputation can be isolated and hospital costs compared to national reference prices. But there are formidable accounting challenges involved (notably in relation to the allocation of overheads and the identification of accountable procedures for such conditions as mental health) and there will still be no way of assessing the costs for a particular patient across the health system or the public sector as a whole.

⁴¹ See for example the UKPDS study which has tracked the long-term health progress and medical costs of more than 5,000 people with diabetes, as a basis for a model that can be used to assess the impact of new forms of treatment or open health programmes.

⁴² See the patient-centred computerised data system developed by the nephrologist (kidney specialist) Victor Pollak from Colorado. On the basis of this system there has been a 25 per cent decrease in mortality and morbidity. Similar savings have been made in staff time spent on record keeping. Real-time feedback allows a more accurate tailoring of treatment to the patient, and the cohort now tracked by his system allows evidence-based assessment of innovations in treatment. The result is a substantial cut in costs. Pollak and his New York colleague Jonathan Lorsch have now gone one step further, and shifted the process of haemodialysis for daytime treatment in hospital to nighttime treatment at home. This was made possible by the real time remote patient monitoring operated by the central information system (which in New York manages all the medical and administrative aspects of 20,000 chronically ill renal patients). As the result of this new treatment, patients no longer require diets, drugs or regular hospitalisation. They have been able to follow a virtually normal daytime life, with 'wellness in-the-foreground' Pollak (1985); Pollak (1990); Pollak and Lorsch (2001). The NHS Care Records Service will provide a major step towards this, in as much as it serves as an infrastructure for patient-centred health records. The issues it faces are buy-in from physicians, how it will be customised and with what clinical detail, and how far it will be able to serve as the basis for person centred healthcare accounting.

⁴³ Bevan (2005).

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