

The Role and Effectiveness
of Collaborative Knowledge
Systems in Health Promotion
and Health Support



**“The role and effectiveness of collaborative knowledge
systems
in health promotion and health support”**

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REPORT SUMMARY

This Report presents the key *practical* outputs of the ESRC project ‘The role and effectiveness of collaborative knowledge systems in health promotion and health support’. Four sets of outputs are included below:

- A typology of health technology collaborative knowledge systems
- A Report on the development and testing of a prototype collaborative knowledge tool
- A policy framework and recommendations to promote the development and use of health technology collaborative knowledge systems
- Principles and Guidelines for the design of health technology collaborative knowledge systems

In addition, the results of the ‘Audit of systems and services’ carried out as part of the project’s research actions, is provided in Annex 1. This sets the context for the development of the ‘Typology’.

Typology

The typology of systems and services was developed from the results of the ‘audit’ (presented in Annex 1 of this Report). A total of forty-seven collaborative knowledge systems providing health information and support services were covered in the audit. Two typologies were produced: a ‘functional’ typology and a ‘discursive’ typology. The functional typology used cluster analysis to classify the systems and services on the basis of a range of distinguishing variables, including: delivery platform; services provided; the key ‘knowledge domain’ covered; the revenue model adopted; the ‘knowledge production’ model adopted; the users of the services provided; the ‘scenarios of use’ implemented; the ‘techniques’ used to promote interaction between stakeholders. The ‘discursive’ typology provides an alternative to the functional (instrumental) model by considering collaborative knowledge systems from the perspective of ‘technicisation’. The typology is developed mainly from the work of Heidegger, Habermas and Foucault and provides a framework for classifying health technologies on the basis of a number of ‘discursive’ properties, including: primary and secondary instrumentalisation; system-lifeworld embeddedness; promotion of marginal practices.

Collaborative Knowledge Tools

This set of outputs covers the ‘action research’ element of the project. It describes how the learning derived from the project’s research actions – review of state of the art; audit of systems and services; results of case study analysis of systems and services - was applied to add value to a large research and technology development (RTD) project called HERO. HERO – health and educational support for the rehabilitation of offenders – was funded by the European Commission to develop methods and technologies to support the offender rehabilitation process. The focus of the project was to build a collaborative knowledge system to ‘bridge’ a range of key moments in the ‘offending life cycle’. HERO targeted two main groups: ‘first time’

offenders, and offenders who were in the process of being re-settled. A key aim of the project was to encourage the different actors in the criminal justice system to 'step into each others shoes', and to use the insights gained from this 'lifeswapping' process to develop new approaches to rehabilitation. The action research involved two activities: firstly, an ongoing activity that focused on contributing to the evolving HERO tools and services (for example through improved website and tools design). The second, more intensive action research activity involved building an additional set of tools and evaluating their value added through an additional pilot site – 'One Spirit'. This new pilot site focused on a new – and key - aspect of the 'offending life cycle': offending prevention (or, as Tom Cruise might have put it, 'pre-crime'). We worked with a group of 'at risk' young people in Hackney, London and with a group of inmates on 'Death Row', San Quentin to develop and test innovative collaborative knowledge tools to deliver health and learning programmes aimed at drugs harm minimisation; sexual health awareness; mental and psychological well-being and skills development. The project was delivered using a 'blended e-learning and e-health' model which included creative activities (singing; song composition; film-making and film-editing; graphic design).

Policy Framework and Recommendations

This set of outputs draws together and synthesises the main conclusions of the project and applies them to produce a policy framework and recommendations to promote the development and implementation of digital collaborative health information systems and support services. The framework is based on a key conclusion of the project: that the health technology domain is unstable, turbulent and rapidly evolving. Within this environment, policy aimed at putting into practice of some of the agendas and instruments aimed at 'empowering' citizens and patients; creating new professional-lay partnerships, and promoting more effective 'self-management' of health, needs to balance and manage three distinctive, and often opposing, dynamics: the integrative dynamic, which is primarily government-led; the hegemonic dynamic, which is essentially market-driven, and the discursive dynamic, which is community-based. The recommendations include: developing policy to balance the needs of the market with the need for socially-embedded and inclusive health support services; promoting the use of novel and hybrid technologies; developing new methodologies that can handle tacit and anecdotal knowledge.

Principles and Guidelines for the design of health technology collaborative knowledge systems

This final set of outputs draws on the policy framework and recommendations to help support effective design, production and implementation of systems and services. These are shaped by a key finding of the project:

The effectiveness of collaborative knowledge systems in providing health information and support services is dependent more on social, cultural, institutional and economic factors than on the 'technical'

properties of the platforms and tools themselves, or on detailed design features, such as graphical user interfaces.

The main – or ‘priority’ – design principles and Guidelines focus therefore on promoting social relevance and cultural meaning. They cover: how to embed technologies in the ‘life world’ and reflect the everyday practices of patients and public; designing for ‘fitness of purpose’ and ‘fitness of context’; developing and applying effective learning and empowerment approaches. The second set of principles and Guidelines focus on ‘fine tuning’ systems. These include: using tools to build in collaborative working in a holistic way; making design more flexible; addressing resistance and poor motivation through good design and good practice.

1. Introduction and Scope of this Report

The RECKS project can be seen as a 'hybrid' project that combines 'research actions' with 'action research'. This is reflected in the aim and key objectives of the project. The main aim was:

- To assess and enhance the role and effectiveness of collaborative knowledge systems in health promotion and health support

The main objectives were:

- to map the distribution and characteristics of collaborative knowledge systems in health informatics
- to identify the main behavioural, cultural, organisational and technical factors constraining the effective use of such systems
- to develop and test a prototype collaborative knowledge production system in a range of action research environments
- to develop a typology of such systems and applications
- to produce good practice guidelines and policy recommendations. and disseminate the results of the project to appropriate stakeholders

In essence, these objectives reflect three distinct, though inter-related modes or phases. The first phase defines a 'research mode', intended to explore the domain of collaborative digital health information and support technologies, and establish theoretical and practical boundaries for that domain. This phase broadly corresponds to the first two objectives.

The second phase takes the research orientation further down the action research route, by applying the practical outputs to the development of collaborative knowledge tools, and then using those tools in a real environment, in order to further deepen the understandings gained through the research activities. This corresponds to objectives three and four.

The third phase reflects a 'practice and dissemination' mode, through which the results of the research activities are deployed to develop a range of project outputs that have a more 'applied' orientation – for example to add value to existing and future health policy initiatives. This broadly corresponds to the final project objective

Phase one - the research mode – was comprised of two research activities ('work packages' in the project workplan):

- Work package 1: Review of State of the Art
- Work package 2: Intensive Case Studies

The **Review of State of the Art** adopted a multi-methodological approach which entailed the following activities:

- Desk research: identifying, collating and assessing literature and other sources of content

- Structured interviews: involving an Advisory Group of experts in the field
- Statistical analysis of secondary data, for example involving analysis of utilization data drawn from technical logs of relevant websites.
- An 'Audit' of specific examples of innovative health technologies providing health information and support services, and involving the use of collaborative knowledge systems ¹. The audit combined secondary data analysis (for example content analysis of documents and web site evaluation) with interviews, to map the size and characteristics of systems and services on the basis of indicators like delivery type; target users; content portfolio and mode of interactivity.

The **Intensive Case Studies** were primarily intended to deepen the understandings derived from the review of state of the art of how collaborative knowledge systems worked in the health domain; what outcomes and impacts were associated with their use, what were the barriers to effective use, and what were the effects of motivational, access and organisational factors in the utilisation and effectiveness of such systems. Two types of case studies were undertaken:

- Analysis of three specific examples of operational digital health information and support services using collaborative knowledge systems, selected to reflect the main types identified in the literature review and audit.
- Two cross-cutting', or thematic case studies reflecting key issues identified in the Review – on finance and the economics of health technologies, and one focusing on health collaboration and partnership innovations that were not enabled by technology.

The results of these two work packages, i.e. the results of the research mode of the project, are set out in two other separate project Reports:

- Collaborative Knowledge Systems in health promotion and health support: Review of State of the Art
- Collaborative Knowledge Systems in health promotion and health support: Case Study Report

In **this** Report, we concentrate on the results and outputs of the second and third phases of the project – the practical and the action research modes. The outcomes that are presented below are as follows:

- Typology of health technology collaborative knowledge systems
- Development and testing of Prototype collaborative knowledge tool
- Policy Framework and Recommendations
- Principles and Guidelines for the design of health technology collaborative knowledge systems

¹ Defined as: technologies which provide for feedback and evaluation of the information provided; enable interaction between producers of health information and consumers; enable the use of tacit knowledge or conversion of tacit into explicit knowledge; and enable different discourses and social constructions of health to be shared

A presentation of the results of the 'Audit of systems and services' is provided in Annex 1. This sets the context for the 'Typology' set out in Section 2 of this Report.

SECTION 2: Typology of health technology collaborative knowledge systems

2.1 Functional typology

The starting point for developing our typology of collaborative knowledge systems was based on an analysis of the technical, institutional, economic and pedagogic characteristics of products and services developed within the health technologies market and the research and technology development sector. The Audit of Collaborative Knowledge Systems in health promotion and health support (described in Annex 1 to this Report) further refined this initial starting position by exploring firstly how the market and research health technology domains had evolved over time, and secondly by focusing in particular on the features of collaborative knowledge systems within the overall health technology environment.

Using the dataset compiled through the audit, a cluster analysis was undertaken to further develop this emergent typology. The cluster analysis used Wards method to promote an optimum cluster solution for the 47 examples of collaborative knowledge systems identified by the Audit, with the following variables:

- The delivery platform (the infrastructure used to deliver health systems and services)
- The services provided
- The key 'knowledge domain' covered
- The revenue model adopted
- The 'knowledge production' model adopted (as reflected in the nature of interactivity between stakeholders)
- The users of the services provided
- The 'scenarios of use' implemented
- The 'techniques' used to promote interaction between actors

All these variables are described in Annex 1 to this Report.

Following a number of iterations, the optimised cluster analysis solution suggested four cluster types. These are described in Table 1.

Table 1: Collaborative Knowledge System – functional typology

	Cluster 1	Cluster 2	Cluster 3	Cluster 4
Description	Basic Information systems	Web-based public health services	Collaborative knowledge constituencies	Highly-integrated, multi-modal
Representation	39%	25%	28%	8%
Delivery	Web/DiTV	Web	Web	Hybrid
Content focus	Mixed	Risk behaviours	Topic-based Interest groups	Mixed
Revenue model	Subscription Public	Partnership (voluntary; public; private)	Public	Mixed
Knowledge production	Transmissive	Expert-expert	Expert-expert	Mixed
Users	Multiple interest	General Public	Communities of practice	Multiple interest
Collaboration techniques	Web site links	On-line surveys	Mixed	Links
Collaboration Functions	Database Email	Ask an expert Chat Email Diagnosis Database SOAPS	Chat Email Database Clinical support Videostream	Comprehensive range

Table 1 shows four main types of system:

- Type 1 – ‘Basic Information System’. – the largest group of the examples surveyed in the Audit, with just under 40% of the total.
- Type 2 – ‘Web-based public health services’ – around a quarter of the total.
- Type 3 – ‘Collaborative Knowledge Constituencies’ – 28% of the total
- Type 4 – ‘Highly-integrated multi-modal systems’ – the smallest cluster with less than 10%.

Examples of each of these types are shown in Figures 1 to 4.



Figure 1: Example of Type 1 ('Basic'): Ivanhoe web site

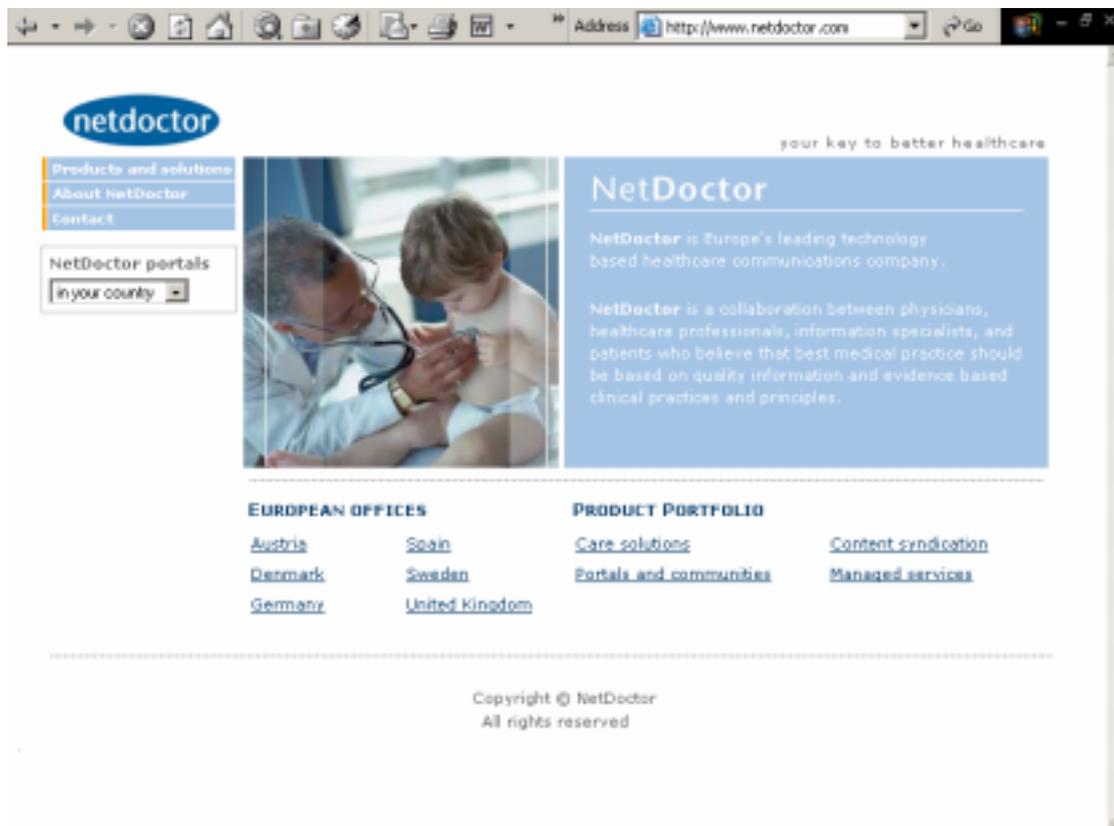


Figure 2 Example of Type 2 ('Public Health Services'): Netdoctor web site



Figure 3: Example of Type 3 ('Collaborative Knowledge Constituencies'): 4WomanGov web site



Figure 4: Example of Type 4 (Multimodal'): Healthology web site
 As Table 1 illustrates, the cluster analysis suggests a typology of systems and services that is differentiated primarily in terms of:

- Audience profile and target user
- Funding and organisational arrangements
- Health content and priorities
- Pedagogic approach and collaboration strategies.

In other words, system and service interactivity and the collaboration strategies adopted is inter-dependent with the ‘health metaphors’ (content configuration) and delivery models (platform; institutional and partnership arrangements; holding techniques) adopted by the service.

Type 1 (Basic Information Systems) are essentially.... providers of basic information. Typical target users are multiple interest groups (diet; sex; beauty; specific conditions like cancer heart disease), reflected in the use of Digital Interactive TV platforms to cover a broad audience pattern – as well as Internet platforms.. Health content is consistent with this broad range of multiple interests, and is typically developed by professionals. The pedagogic approach adopted is correspondingly transmissive (conventional top-down expert-consumer), and the strategies, techniques and devices used to promote collaborative knowledge production and interactivity are minimal (typically links to related web sites; database searching and e-mail).

Type 2 (Web-based public health services) reflect a more focused and less differentiated target user configuration – and hence content repertoire. The main focus is on risk behaviours (for example CHD; sexual health). This type of service exhibits a greater range of strategies and devices used to promote interactivity and collaboration than the first Type (incorporating for example content evaluation and editing functions). However, the typical knowledge production and collaboration model adopted is still expert-focused. In this case, collaboration reflects networking between a range of health professionals, whose pooled knowledge and collaborative results are then used as an evolving resource for professionals themselves, and then passed on to ‘lay’ consumers. It is significant that the typical funding model – and organisation structure – involves partnerships between professional groups, public agencies and the voluntary sector.

Type 3 – ‘Collaborative Knowledge Constituencies’ are arguably the most highly developed type of collaboration system. Essentially the main characteristic of this type is its role in developing communities of practice. In some cases, these communities of practice focus on community-based organisations or common interest groups. The example shown in Figure 13 - 4Woman.Gov . – is one such service, a national web site funded by the Australian government to promote knowledge about womens’ health through pooling of knowledge and resources. But this tends to be atypical. The typical scenario of use is to support inter-professional working and continuing professional development. This type therefore contrasts with Type 2 – which uses inter-professional networking as a bridge to migrate health knowledge to consumers – since knowledge flows tend to circulate within and between professional networks, rather than ‘bridged’ to patient and public networks. The greater degree of commitment to a collaboration model, and the professional-led orientation of this type of service is reflected by a broader

and more sophisticated range of interactive functionalities and collaboration devices, including for example clinical decision support tools and evidence bases.

Type 4: Highly-integrated multi-modal systems' – constitutes the smallest cluster of services, and reflects what might be termed the 'emergent generation' of convergence technologies. Convergence in this sense means the integration and configuration of both technical platforms and content. The example shown in Figure 14 – the 'Healthology' portal – is a typical example. Healthology can perhaps best be described as a 'franchising and branding' web-based service for health information. Basically Healthology is a large evolving knowledge base of health content, created by an extensive network of health specialists. It combines video streaming media with conventional written articles on health issues to provide content that is then 'branded' to suit an individual 'downstream' provider, typically a health website or individual physician. The main aim is therefore to add value to existing digital health content providers by 'enriching' their existing content base. The distinguishing feature of this type of service is that interactivity and collaboration are geared towards providing a seamless, branded 'look and feel' that is shaped both by the target consumers of the recipient downstream health information provider, and the commercial partnerships whose aim is to sell products to these consumers. Collaboration in this context constitutes a radically different model, approach and strategy from Types 2 and 3, whose objectives are, broadly, to facilitate the production of new knowledge through networking and knowledge sharing.

2.2 Discursive typology

2.2.1 Context: technology and post-modernism

In Annex 1 of this Report, it is argued that a key distinction in the context of the evolving 'knowledge society' needs to be made between the instrumentality of health technologies, in the sense of acting as tools to facilitate the efficiency and effectiveness of medical procedures and practices (much as, say, a saw is instrumental in the practice of carpentry) and their capacity to reflect and shape 'communicative practices'. The 'functional' typology outlined above in Section 2.1 defines and classifies collaborative knowledge systems and services primarily on the basis of instrumentality.

However, it is equally important to understand collaborative knowledge systems in their role as a form of mediation between actors engaged in social interaction, and their position in social and personal relations. In this Section, we therefore develop an alternative typology to the functional (instrumental) model by considering collaborative knowledge systems from the perspective of their 'discursive properties'. The conceptual starting point for this typology draws on a number of positions in 'post modern' social science and philosophy. The typology is developed mainly from the work of Heidegger, Habermas and Foucault, and also draws on concepts derived from the work of Marcuse, Gramsci, Simondon and Latour.

A common thread that runs through the work of these and other post-modern theorists is the status of technology in defining people's essence as social beings. The starting point through which ideas around society and technology are explored is the notion of 'self'. Both Heidegger and Foucault, at least in their earlier works, categorically reject the long established Cartesian idea of a self-transparent subject and the related Kantian ideal of autonomous agency. As Heidegger (1977) puts it:

"The idea of a subject which has intentional experiences encapsulated within itself is an absurdity which misconstrues the basic ontological structure of the being that we ourselves are".

Heidegger therefore substitutes for 'subject' a rather shadowy entity called 'Dasein' the 'being for whom being is an issue'. Dasein is in essence a non-autonomous, culturally-bound mode of being characterised by 'thrown-ness' – a mode of anxiety derived from the 'inauthenticity' of its relationship with the object world. Similarly, in 'The Order of Things', Foucault argues that the notion of a self-transparent subject is equally absurd, since the self is no more than a construction of our discourses. For Habermas, it is impossible to conceive of self without reference to how individuality is socially constructed through 'communicative practices'.

All three philosophers make a clear connection between this discursive state of selfhood and what they see as the key defining feature of post-modern society – technicisation.

Hediegger's position on technicisation is arguably the most extreme. As Feenberg (1996) points out, Heidegger's view is that technology is relentlessly overtaking us. Modern society is engaged in the transformation of the entire world, ourselves included, into "standing reserves," raw materials mobilised in technical processes. An "objectless" world of functions replaces a world of "things" as the vehicle for our engagement with 'being'. Modern technology destroys the essence of materials and artefacts by 'de-worlding' them through a process of 'enframing'. Enframing essentially means that artefacts are engaged with purely in terms of their instrumentality. Habermas (1984) does not see post modern society in quite so monolithic a way as Heidegger. He makes a key distinction, for example, between system-regulated rational institutions like business markets and governmental bureaucracies, and 'lifeworld' – the space in which everyday communicative practices are played out. However, Habermas too strongly argues that the central pathology of modern societies is the colonisation of lifeworld by system. This process happens because the defining characteristic of system-regulated institutions - success oriented action – is extended beyond its legitimate sphere and begins to dominate and take over the communicative practices of everyday life. Habermas terms this the "technicisation of the lifeworld".

A crucial element in the process of technicisation, and the subordination of Dasein and Lifeworld to systems, planning and technical process is scientific knowledge. Foucault arguably provides the most comprehensive – and persuasive – analysis of the relationship between modernity, technology and scientific knowledge. A defining characteristic of post-modern society for Foucault is the reification of the subject. This happens through the interplay of three dynamics: dividing practices, scientific classification and subjectification.

Dividing practices refers to the exclusion and control of social groups via the application of scientific discourses and procedures, for example the isolation of lepers in the Middle Ages; the confinement of the poor in poor houses, and the confinement of the homeless in institutions like the Hospital Generale. Scientific classification denotes the mechanism through which the intricacy and holism of 'lifeworld' becomes reconstituted, separated and divided into constituent – and autonomous – categories such as life, labour and language. This process is mediated through the formalisation of discourses of everyday life, an important example being the medicalisation of knowledge about health, and its appropriation by professionals. It is accompanied by a 'cult of specialisation' - life and language acquire a high degree of internal coherence. By themselves, these two dynamics cannot totally account for the reification of the subject. This requires the active participation of the subject itself. This participation is instituted through the process of 'subjectification', through which individuals achieve self-understanding via interaction with 'mediators'. Mediators are essentially authority figures. In classical and medieval epochs, they include priests and shamans. In the post-modern period, they encompass clinicians; psychoanalysts, teachers, chief executives.

What Foucault is essentially arguing here is that post modern society encourages the false perception that people can arrive at a state of self-awareness through a process of self-examination. More importantly, this process of self-awareness can only be properly achieved through engaging

with mediators – through the guidance of the benevolent teacher; through painful analysis on the therapists couch; through the physician’s technical examination. As Foucault points out in ‘The History of Sexuality’, the common denominator of self-awareness through examination is ‘confessional practices’. This is an important concept for understanding the role and potential of health technologies. Foucault’s elaboration of confessional practices reflects his broader analysis of a shift in cultural practices that developed from the classical era through Christo-Judaism and through to the present day. This shift has been marked by a transition from what Foucault terms ‘practices of the self’ through a ‘culture of the self’ to the present day ‘cult of the self’, exemplified in the current preoccupation with ‘self-analysis’ and ‘body image’. In the classical period, the dominant relationship between self and body can be defined in terms of ‘*epimeleia heautou*’ - taking care of oneself. This developed over long period from paganism through the Stoics to Greco-Roman aestheticism. In this cultural sphere, technologies were applied to ‘taking care of the self’. For example, cosmology and physics were essentially tools for understanding the position of the self in the world, not the world itself. Foucault argues that historically techniques and tools evolved through which ‘practices of the self’ could be carried out through the development of ‘literature of the self’. In classical times, these took the form of diaries, private notebooks and other examples of *hypomnemata* (personal narratives and individual ethnographies). However, as a result of the transition from practices of the self to the culture of the self in Christianity, knowledge and the development of ‘techniques of the self’ became put to work in the exercise of pastoral power. *Epimeleia heautou* gave way to *epeimeleia tonallon* – essentially taking care of others. Particularly from the seventeenth century onwards, this pastoral power is reified in the annexation of knowledge about the body, about health, and about techniques of the self – by professionals: surgeons; public health administrators; psychiatrists.

Working with these concepts, one of the key objectives in our work towards developing a ‘discursive’ typology of collaborative health technologies was to explore the hypothesis that the development of new forms of digital health information and support systems could perhaps be opening up spaces for the re-emergence of forms of *hypomnemata* and, more broadly opportunities for the development of new forms of ‘practices of the self’. Put simply, our hypothesis is that, within the emergent ‘Knowledge Society’, tools and services like chat rooms, annotations systems, enriched document systems and distributed knowledge bases provide a potentially rich source of *hypomnemata* to enable citizens and patients to become actively engaged in developing ‘techniques of self-mastery’. This rationale is supported by other work on the systemic features of post-modern society. For example Giddens. has argued that the increasing pervasiveness of the ‘Knowledge Society’ has opened up new opportunities to enable ordinary people to become their own personal ‘social laboratories’, carrying out everyday ‘experiments with the self’, particularly utilising information from the Internet. Giddens (1994; 2001) argues that the proliferation of social movements and self-help groups in recent years is directly related to the growth of the information society, and reflects both this heightened self-reflexivity and the effects of instantaneous global communication. Such movements have played a major role in retrieving power from ‘experts’ and in the lay retrieval of expertise.

2.2.2 Primary and secondary instrumentalisation

To understand how this re-emergence of practices of the self might come about, it is necessary to unpack further what post-modern theory has to say about the relationships between technology, self-awareness and action.

Our starting point is the properties of technical objects, in relation to the processes through which they become, to use Heidegger's term 'de-worlded' from everyday life. Feenberg (1991; 1996) offers a powerful conceptual and analytical framework to illustrate what happens to technical objects in a world of technicisation, a key outcome of which is the separation of a function from the continuum of everyday life. The essence of the framework is Feenberg's definition of 'technique' - which can be defined as the interplay between two forces: primary and secondary instrumentalisation.

Primary instrumentalisation characterises technical relations in every society, although its emphasis, range of application and social significance varies. It can be summarised as four reifying moments of technical practice:

- Decontextualisation – the 'de-worlding' of technical objects. This occurs through their artificial separation from the context in which they are originally found so as to be integrated to a technical system.
- Reductionism - the process in which the de-worlded things are simplified, stripped of technically useless qualities, and reduced to those aspects through which they can be enrolled in a technical network.
- Autonomisation - the subject of technical action isolates itself as much as possible from the effects of its action on its objects. Technical action autonomises the subject through dissipating or deferring feedback from the object of action to the actor. The subject is largely unaffected by the object on which it acts.
- Positioning - the ways in which 'technical' or technicised subjects turn the properties of an object to the laws and agendas of technicisation. For example, positioning the properties of a circuit board to create a network of surveillance systems.

Primary instrumentalisation can be seen in many ways as the essential dynamic of technicisation, and the reason why both Heidegger and Habermas perceived technology in such an essentialist mode – inexorable, overwhelming and destructive. However, Feenberg suggests that primary instrumentalisation operates in a dialectic with what he calls 'secondary instrumentalisation'. He says that:

"This list of primary instrumentalisations does not exhaust the meaning of technique. Technique also has integrative potentialities that compensate for some of the reifying effects of the primary instrumentalisation. Here technical systems turn back on themselves and their users as they are embedded in their wider social and natural context, reappropriating some of the dimensions of contextual

relatedness and self-development from which abstraction was originally made in establishing the technical object relation”

Feenberg's concept of secondary instrumentalisation also embodies four dimensions or 'moments':

- Systematisation – the argument is that decontextualised technical objects must be combined with other technical objects and re-embedded in the natural environment in order to function as an actual device. Systematisation is the process of making these combinations and connections. This leaves room for social interests and values to intervene in the process of systematisation.
- Mediation - in all societies, ethical and aesthetic mediations supply the simplified technical object with new secondary qualities that reinsert it into its new social context.
- Vocation – the autonomisation of the technical subject is mediated through the acquisition of 'craft'. Acquiring vocational identity and skills engages the subject in a community which can then involve the subject in the life of objects.
- Initiative – corresponds to 'positioning' but focuses on voluntary cooperation in the coordination of effort. It has the potential for reducing alienation through substituting self-organisation for control from above. In the sphere of consumption, informal coordination often appears as the users of products appropriate them for unintended purposes

2.2.3 The 'technical code'

It can be seen that the mediating influence of secondary instrumentalisation has the capacity to both ameliorate the 'de-worlding' effects of technicisation, as well as opening up spaces through which subjects can engage more authentically with 'objects' and with the lifeworld. This brings into play a second key concept – the idea of the 'technical code'. In conventional, deterministic interpretations of technological development, there is an assumption that innovation progresses in a stable, linear, evolutionary process. A technical artifact originates as a basic, autonomous innovation. As it develops, its essential technical essence becomes refined, embellished and improved through re-engineering and the application of standards. This developmental trajectory comes about as a result of the inherent properties of the object itself. However, as a number of sociologists of technology point out, technological inventions are both socially constructed and they offer a multiplicity of developmental trajectories. Pinch and Bijker (1986) illustrate this with reference to the evolution of the 'racing bike'. It is commonly assumed that modern bicycles emerged through the evolutionary improvement of contraptions like the Victorian 'penny farthing'. Modern racing bikes mark a tributary of specialised development from the 'standard' bike which originated from the penny farthing. Yet as Pinch and Bijker point out, the 'penny farthing' was in fact built as a racing machine. From the 1870's, a vast number of racing clubs came into being whose sole purpose was to encourage and legitimate competition (races, time trials and so on) between these machines. If the modern racing bike does have a lineage, it is rooted in the 'safety

bicycles' that emerged in Victorian times to provide a less taxing alternative to the 'penny farthing'. The point is that racing cycles and 'safety' cycles were two different technologies. Although the safety design eventually emerged as the dominant form of bicycle, the 'innovation space' in which bicycles developed in their early gestation was characterised by a number of possible innovation scenarios. Pinch and Bijker (1984) call this technical ambiguity 'interpretative flexibility'.

More importantly, not only do technological innovations embody technical ambiguity, they also present what Feenberg (1996) calls 'civilising choices'. In the case of the bicycle, argues Feenberg, issues of design and development were shaped by a 'contest of meanings' – between the bicycle as a mass transportation tool; the bicycle as a sportsman's toy, and so on. At the genesis of technological innovation, these social constructions and meanings are up for grabs. There is a relatively short moment of what might be called 'hermeneutic flux' before the technology becomes 'coded' and freeze-framed through the application of standardization and standards; it becomes appropriated into fixed modes of production, and it becomes reified through legitimated codes and practices of cultural consumption. Following stabilisation of the technological innovation, the technical code will determine the range of configurations of possible lifestyles that can be associated with the particular technical object. The technical code therefore expresses the "standpoint" of the dominant social groups at the level of design and engineering.

At least two significant opportunities for 'lifeworld engagement' therefore arise for the estranged and alienated 'subject' through the operation of the technical code. Firstly, and most obviously, within the 'hermeneutic flux' created at the inception period of invention and development – where opportunities present themselves to invest social meaning within the design. Secondly, through successive iterations of design modification. The 'freeze-framing' of technical objects through technical coding does not mean that they remain fixed and immutable. As objects are deployed and utilised over time, they become changed. This transformation process mirrors on the one hand technical rationality, but also social, discursive and reflexive meaning. Although the dominant 'bias' of technology is functional rationality, the 'double aspect' property of the technical code, as Feenberg calls it, allows for social shaping. However, the mediation of social meaning within technology is a complex process. Simondon (1958), for example, argues that technologies adapt to their multiple social milieux through a process of 'concretisation'. Developed technologies tend towards achieving a kind of equilibrium in response to both physical and social transformational pressures by configuring a range of enhancements, elaborations, refinements and ornamentations in a single efficiency-oriented design. As Latour points out, where the context of use of the innovation is primarily social, 'delegation' of a social rule to a device occurs. The social imperative, and social constraints of the device become internalised, to the extent that they become 'invisible', and the device appears to be characterised purely by technical rationality.

For these reasons, 'double aspect theory' brings into play the third key conceptual perspective that needs to be explored: the nature and application

of action within technicisation. Since the operation of the technical code generates 'contests of meaning' and implies 'civilisational choices', this presents society and its constituent members with problems and dilemmas: how to understand and manage contests of meaning and civilising choices; how to engage meaningfully in the dynamic between primary and secondary instrumentalisation; how to reveal delegation.

It has been argued that post-modern theories virtually reject all notions of choice, action and freedom, or at least view the prospects for authentic engagement with the world of technicisation with deep scepticism. In early Heidegger, Foucault and Habermas, for example, the very nature of 'thrownness' and the operation of the trilogy of dividing practices, scientific classification and subjectification negate all pretensions to autonomous agency. The pervading penetration of rationalisation, efficiency and systems into the lifeworld and into communicative practices creates its own all-embracing discourse. Technicisation appropriates the processes and mechanisms of knowledge formulation, and stifles or neutralises all forms of counter-discourse and practice. Other writers like Marcuse (1966) and Gramsci (1971) have referred to the ways in which post-modern societies have developed mechanisms to exert hegemonous control over discourse and consciousness, to the extent where technicisation becomes perceived as the 'natural' order of things. More importantly, it is the subordination of social meaning within the 'technical object', an end towards which the process of technicisation itself is directed, that reinforces this perception of a natural order of things. As Feenberg points out, Foucault argues in his theory of power/knowledge that modern forms of oppression are not so much based on false ideologies as on the multiplicity of technical "truths" among which the dominant hegemony selects the means to reproduce the system. So long as that act of choice remains hidden, the deterministic image of a technically justified social order is projected.

2.2.4 Action: authentic resoluteness and marginal practices

However, post-modernism does leave some room for manoeuvre for autonomous agency. In early Heidegger, only 'thinkers' have the power to disclose a new world – but later Heidegger suggests that anyone can step into a plurality of worlds and facilitate a change in society's practices. Similarly, Foucault initially totally rejects the idea of autonomous agency as unthinkable, not least because subjects are quite simply, powerless. The totalising tendencies of post-modern society mean that power is not exercised by modern subjects, for example through self-examination and psycho-analysis; rather, power creates them. Thus the search for meaning is not liberating but enslaving.

"[There are] two meanings to the word subject . . . The subject subjugated to the other through control and dependence and the subject attached to its own identity through consciousness or self-knowledge. In both cases the word suggests a form of power that subjugates and subdues".

Yet, as Dreyfus (2004) points out, Foucault still has a robust concept of freedom, and he suggests that freedom is the power to change what is taken

for granted and the capacity to change oneself. Two particular concepts are important in this shift in emphasis: 'authentic resoluteness' and 'marginal practices'.

On the one hand, Heidegger is unequivocal in his assertion that 'Dasein cannot get behind its thrownness' – it must act on the basis of taken for granted practices it can never fully grasp. He argues that the dominant mode of engagement with 'thrownness' is one of anxiety. But if Dasein does not allow itself to become overwhelmed, if it resolutely 'holds on' to anxiety, this makes it sensitive to the possibility of interacting with others to create some cohesive form of action through everyday practices. For everyday practice to have meaning some cohesive medium must be available to integrate the 'scattered practices' of the group. In the past, such kinds of media were present to hand in the form of socially defined and legitimated spaces – for example the temple. The temple serves as an 'equipmental whole', to use Heidegger's term within which 'skilful coping' – the everyday set of skills humans have to enable them to operate within the world – can be applied in some form of authentic action. So 'authentic resoluteness' is essentially the freedom available for Dasein to change itself by modifying its background practices. In this way Dasein can live a life worth living, even though it can never be a self-sufficient, lucid, autonomous subject.

In much the same way that Heidegger developed the idea of a 'thinker' as a type of Dasein who is able to act resolutely in order to create opportunities for 'authentic action', Foucault initially developed the notion of a 'discourse founder' who opens up possibilities for new forms of discourse and by extension new forms of communicative action. But later, he seems to argue that anyone can operate within 'disclosive domains' by engaging in 'marginal practices'. In his last major work Foucault turns to an issue that he had hitherto avoided in his sustained and prolonged attack on the forces of dividing practices and scientific classification – the issue of individual conduct and ethics. In this shift towards at least some partial recognition of individual autonomous agency, Foucault seems to find the locus of individual conduct and ethics in the idea of 'taking care of the self', referring back to the 'techniques of self-mastery' through which in classical times Greek individuals sought to transform themselves:

"It was [the] theme of the care of oneself, consecrated by Socrates, that later philosophy took up again and ultimately placed at the center of that "art of existence" which philosophy claimed to be. . . . Around the care of the self, there developed an entire activity of speaking and writing in which the work of oneself on oneself and communication with others were linked together."

2.2.5 Framework for the discursive typology

What contribution can a post-modern paradigm, and the concepts explored in the previous sections, make towards understanding and developing a typology of digital health information and support technologies?.

- They offer opportunities for subversion of the totalizing tendency of 'scientific classification' (for example by promoting the use of tacit knowledge in developing evidence bases for health)
- They incorporate tools that can potentially replicate the function of classical 'techniques of self-mastery' and 'literature of the self' (for example through weblogs and chat rooms)
- They allow 'technical subjects' opportunities to shape the production of scientific knowledge
- Digital health information and support services are still evolving and are still 'contested spaces'. The process of technical coding is still in a state of flux. This provides opportunities for people to invest meaning and social shaping in the emergent technologies. This in a superficial sense can be reflected in collaborative input into design and functionality development (for example user interfacing).
- In a deeper sense, digital health information and support technologies reflect the modes of 'secondary instrumentalisation'. By virtue of their nature as tools to promote collaborative knowledge production' these technologies in principle offer more scope than most for engaging in 'marginal practices' (for example by supporting 'alternative' medical practices) and for promoting 'mediation', 'vocation' and 'initiative'.

On this basis, Table 2 provides a framework for our alternative 'discursive' typology. As table 2 shows, there are three 'meta-level' modes that situate the typology within its historical and socio-cultural context. Each of these modes is associated with a number of 'moments' – key defining dimensions that characterize the essence of each mode – and in turn with a number of 'analytics' against which each mode can be assessed. This does not suggest that each analytic constitutes a 'variable' in the same way that nomologist paradigms associate variables with metrics and measurements; rather, following Strydom (1990) the analytics are used as normative assessment tools. The three discursive modes are:

Technicisation – this mode explores the role and status of digital health technologies in terms of tensions and dynamics between 'system' and 'lifeworld'. The systems and technologies are analysed in terms of attributes like:

- The kinds of discourses and 'cultural logic' expressed in the content used in systems and services
- The extent to which these discourses are connected with the everyday lifeworld
- The extent to which knowledge is medicalised and/or presented in ways that are accessible to non-experts

Table 2: Discursive typology framework

Mode	Moment	Analytic
Technicisation	Scientific classification	Separation and classification of health discourses Connectivity of discourses and everyday life Degree of medicalisation of knowledge
	Dividing practices	Confessional practices Degree and mechanisms of control
	Subjectification	Techniques of mediation
	System-orientation	Success-life world balance
	Equipmental-coping	Capacity for applying and developing 'coping' skills within collaborative space
Technique	Primary Instrumentalisation	Decontextualisation – embeddedness of tools and functions in lifeworld. Reductionism – user-centeredness and usability of functionalities Autonomisation - availability for feedback and knowledge co-production functions Positioning – degree to which users experiences are applied to 'technicisation' functions (e.g. production-consumption)
	Secondary Instrumentalisation	Systematisation – extent of user involvement in continuing technical re-engineering and adaptation Mediation – nature of ethical and aesthetic mediations Vocation – nature of skills utilization and acquisition. Initiative – nature and degree of collaboration and collegiality
	Technical code	Engagement in design and engineering process Standardisation processes
Disclosive Reflexivity	Marginal practices	Capacity for opening up new discourses
	Techniques of self-mastery	Cult of self-culture of self Use of personal narrative

- How mediators are deployed in developing knowledge (for example in functionalities like 'ask an expert')
- Extent to which system and success-oriented discourses dominate over 'lifeworld' discourses

Technique – this mode explores the interplay between primary and secondary instrumentalisation in relation to digital health information and support services. Examples of the analytics used to define primary and secondary instrumentalisation are:

- degree and nature of user engagement in design and social shaping of systems and services
- nature and effects of evolution and deployment of standards
- ways in which refinements and ornamentations are introduced
- nature and extent of collegiality within collaborative practices

Disclosive reflexivity focuses essentially on the opportunities created for marginal practices. These include:

- Development and deployment of ‘techniques of self-mastery’ e.g. chat rooms; ‘true stories’; weblogs

2.2.6 Application of discursive typology

The cases covered by the Audit were categorized and coded using a coding frame based on the discursive typology framework discussed above. Cases were coded for a range of analytic dimensions for which data were available (or from which data could be extrapolated). The data were compiled from content analysis of documentation (including web site content) using NVivo. Table 3 shows the analytic dimensions used, together with the type of indicators and measures adopted for each analytic.

Table 3: Indicators and Measurements

Analytic	Indicators/Measures
Separation and classification of health discourses	Ontological structure and classification system of content
Connectivity of discourses and everyday life	Use of ‘holding techniques’ (e.g. quizzes)
Degree of medicalisation of knowledge	Content balance – predominance of evidence base and peer-reviewed content
Confessional practices	Use of expert mediation (e.g. ‘ask an expert’)
Degree and mechanisms of control	Pedagogic model – content development and editorial approach
Techniques of mediation	Use of decision support and diagnostic tools
Decontextualisation – embeddedness of tools and functions in lifeworld.	Mix of content and relevance to target users
Reductionism – user-centeredness and usability of functionalities	Platform functionalities; evidence of usability
Autonomisation - availability for feedback and knowledge co-production functions	Use of co-production and evaluation tools (feedback forms; SOAPS)
Initiative – nature and degree of collaboration and collegiality	Processes for engagement in Information and support services production processes
Capacity for opening up new discourses	Opportunities and functionalities for ‘marginal practices’
Cult of self-culture or culture of self	Content analysis (e.g. balance of lifestyle v community health content)
Use of personal narrative	Use of tools and functions for developing ‘narratives of the self’ (e.g. ‘True Stories’; video diaries)

Values were assigned for each case on each indicator on the basis of the degree to which they expressed the analytic dimension. The values were compiled using item analysis carried out by a criterion group composed of the

research team. These indicators are heuristic expressions of the dimensions formulated in the discursive framework (as distinct from ‘metrics’).

Correlation of the data (using Spearman rank order and crosstabulation) identified six key discriminating variables that differentiated the audit examples. These are summarized in Table 4.

Table 4: Key discriminating variables

Variable	Value	% cases
Discourse focus	Commodified (focus on lifestyle and consumption)	8
	Fragmented (focus on interest groups)	70
	Systems (focus on professional networks)	3
	Lifeworld (focus on community)	19
Control of knowledge	Scientific practice-led	86
Techniques of Mediation	Confessional practice (use of expert as mediator)	45
Scientific classification (focus on medicalisation of discourse)	High degree of focus	42
Use of techniques of self-mastery	Extensive use	24
Autonomisation	High degree of feedback and knowledge production functions	49

The results in Table 4 suggest that digital health information and support systems constitute a volatile and evolving domain, which reinforces the picture painted by our review of state of the art. On the one hand, there is an impression that current systems and services conform to a ‘technicisation’ paradigm, characterized by the separation and classification of health discourses, and their divorce from social practices and lifeworld. The range of discourse identified (discourse focus), as illustrated by the type and balance of content, is heavily weighted towards fragmented interest groups and lifestyle and consumption issues. Knowledge production is scientific-led and medicalised, and there is a high level of use of experts and professionals as ‘knowledge mediators’. On the other hand, there is some evidence that digital health technologies are beginning to reflect the development of ‘techniques of self mastery’ and ‘autonomisation’ – functionalities to promote co-production of knowledge (for example through the deployment of extensive community-based discussion groups; through the use of ‘true stories’ and other ‘narratives of the self’).

Cluster analysis of these discriminating variables (Wards method) was used to further develop the discursive typology. However, the outcome did little to promote further illumination of the discursive world of digital health technologies. Three clusters were identified (Table 5)

Table 5: Discursive typology

Cluster	% cases	Characteristics
1	86	Technicised
2	11	'That's life'
3	3	'Home Expert'

As Table 5 shows, the cluster analysis further supported the picture painted by our preliminary analysis of a broadly 'technicised' domain, but one characterised by volatility and evolution. 86% of the sample of systems and services were allocated to one cluster. As discussed above, this type is dominated by systems and services that deliver primarily 'expert-led' information and support, but some of the systems do provide 'socially embedded' technologies and functionalities to promote co-production of knowledge. The other two clusters identified constitute a very small proportion of the population – 11% and 3% respectively. Type 2 might perhaps be described as a 'That's Life' cluster. It features hybrid Digital TV/internet systems with extensive use of Discussion Boards; True Stories and listmailing. The discourse focus is on 'common interest' topics, linked to everyday life issues (weight loss; pregnancy; diet; smoking; snoring) but with a strong emphasis on diet and nutrition. Type 3 could be described as 'Home Expert'. This group (comprised of only two cases) constitute the most highly 'technicised' of the audit population. Both cases focus on specific medical conditions – eating disorders and chronic illness. Both are highly expert-led, providing support services to users via a home-based health monitoring approach, using expert system; diagnostic and 'tele-therapy' tools.

End note

The discursive typology worked as a conceptual framework, but was problematic to apply. Three factors (at least) are at work here. Firstly, it is difficult to operationalise hermeneutic methodologies when using heuristic measurements. One is always confronted by the urge to take comfort in the tyranny of numbers – which leads, in this case, to the compilation of a numerical-based data set from content analysis using NVivo software. Second, the sources deployed to apply the framework were highly variable. We had to work with an uneven, and eclectic set of data, drawn from web site content, documents of variable quality and patchy and primary data drawn from interviews. Third, the data universe itself is sparsely populated. As illustrated by the results of the 'audit', collaborative knowledge systems in the health domain constitute an exotic species. Moreover, the universe constitutes an evolving, unstable and contested domain. This in itself could be construed as evidence of a 'hermeneutic flux' (described above) in which innovative and 'authentic' technologies could develop in the future. At this point in time, however, our attempt to apply a 'discursive typology' has proved to be modest in its execution, providing at best a demonstration of how an 'alternative' methodology can be applied.

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SECTION 3: Tools Development and Action Research

3.1 Introduction and planned scope of the work

The project workplan specified a particular set of activities (work package 3) aimed at putting into practice the learning derived from the research activities (state of the art review, audit of systems and services, typology and case studies) in order to deepen understandings about how collaborative knowledge systems in health promotion and support worked, and how their effectiveness could be enhanced. The aims of this work package, as specified in the workplan, were:

- To extend the results of the case study research by actively involving users in developing and evaluating enhancements to the collaborative knowledge production systems used to deliver health information and support
- To add practical value to the existing systems being researched

The approach as specified in the workplan entailed an action research methodology incorporating three elements:

- Firstly, introducing some of the learning derived from the research actions into two of the 'live' digital health services covered in the case studies, with a focus on decreasing 'motivational resistance' to the use of the services, and improving accessibility to the services.
- Secondly, working to improve the effectiveness of one of the four Digital Interactive Television (DiTV) pilot experiments implemented by the Department of Health. These pilots included: adding value to NHS Direct (nationally and locally); providing targeted information for pregnant women and nursing mothers, and for those at risk of cardiac problems.
- Thirdly, working to improve the effectiveness of the HERO project. HERO - health and educational support services for the rehabilitation of offenders – is a pan-European research and development (RTD) project funded under the European Commission Information Society Technologies (IST) Programme. HERO developed information and support services (including mental health diagnostic tools; sexual health lifestyle assessment and drugs harm minimisation information) for two groups of prisoners: 'first timers' and those about to be released. It provided these services in eight sites in the UK, Greece, Italy and Germany.

The action research methodology was to:

- assess the effectiveness of the existing technical scenarios
- on the basis of the results provide inputs towards enhancing the functionalities of the tools and services
- assess the impact of these enhancements.

'Enhanced functionalities' was defined as:

- improvements to the 'content model' and content balance provided
- modifications to the 'training model' adopted (all health promotion and support technologies embody some form of pedagogic approach and model) and enhancements to the user interface
- enhancements to support tools (for example search engines; advisor agents; user profiling tools)
- adding and/or enhancing feedback tools (for example annotations and 'seals of approval' (SOAPS)).

The overall methodology incorporated elements of the Information Systems Use (ISU) model, which is essentially a collaborative iterative prototyping approach that represents a departure from conventional 'engineering-driven' approaches to systems development. As Hales (1993) puts it "design professionals working in 'engineering mode' still abstract the design from the use practice... what needs to be designed is practices rather than simply apparatuses". In the ISU model, action research is part of a 'designing organisation' in which self-design by members is the fundamental mode of operation, and where research addresses the 'social practices' surrounding the use of health technology rather than engineered tools themselves.

The data gathering techniques used within the overall ISU approach included:

- Monitoring and Review (M&R) workshops
- Focus groups
- Retrospective critical incidents and task analysis
- On-line tools (feedback forms; annotations; user profiling tools).
- Self-administered questionnaires (SAQ's)
- Observation

3.2 Actual scope of the work (what actually happened)

The action research workplan (as set out in the preceding section) had two key characteristics: one, it was ambitious and two, the operationalisation of the plan was highly contingent on 'external' variables (not least gaining access to and engaging meaningfully with the chosen action research environments). Against this background, a number of factors conspired to constrain the scope of the plan.

With regard to the Digital Interactive TV pilots, government spending reviews, and the results of the evaluation of the initial pilots, resulted in the suspension by the Department of Health of the planned Phase II of the Programme. This meant that we were unable to gain access to the pilot sites (since they literally ceased to be operational). Our response to this situation was:

- To analyse the data produced from the formal evaluation of the initial Phase I programme (derived from an evaluation conducted by a team from City University, London)

- To supplement these data with interviews with managers of the DiTV pilots

With regard to the case study examples, the management environment of the services was resistant to fully engaged action research. This meant that it was only possible to implement restricted interventions in these cases. Essentially, we worked with two of the case study examples – DipEx and MEDCOM – through: introducing user feedback and consultation functions into the service delivery functions; implementing monitoring and review workshops with staff. Activities included the setting up of on-line feedback mechanisms (user response questionnaires and Discussion Groups) through the RECKS web site (Figures 5 and 6).

The screenshot shows a web browser window displaying the RECKS website. The page has a purple header with the RECKS logo and navigation links for 'About', 'Downloads', 'Links', and 'Contacts'. The main content area is titled 'DIPEX website questionnaire' and is divided into sections. The first section, 'Section A: Background to Involvement', asks users to describe themselves. The second section, 'Q2. How often have you visited the DIPEX web site?', offers frequency options.

RECKS > About > Downloads > Links > Contacts

DIPEX website questionnaire

Section A: Background to Involvement.
In this section, we would like to find out about how and why you visited the DIPEX web site.

Q1. Which of the following best describes you now...
(please tick more than one answer if appropriate)

- A health professional
- A member of the public who is concerned about someone else's health
- A patient or member of the public who has a health condition
- Someone who is just interested in health matters
- Researcher
- Other

Q2. How often have you visited the DIPEX web site?

- Only once
- 2-3 times
- 4-6 times
- Over 7 times

Figure 5: RECKS on-line feedback questionnaire

Discussions and Feedback		Topics	Posts	Last Post
the RECKS Online Conference				
Empowerment and motivation Empowerment and motivation	6	6	07 Jun 2004 1:42:14 PM by: administrator	
Funding and Economics Funding and Economics	4	4	07 Jun 2004 1:50:25 PM by: administrator	
Knowledge creation and its impacts Knowledge creation and its impacts	3	4	01 Jul 2004 11:50:27 AM by: shirley	
Images of health in the Knowledge Society Images of health in the Knowledge Society	4	4	07 Jun 2004 2:00:20 PM by: administrator	
Guidelines on Policy and Design for IHTs This Discussion Group gives you an opportunity to contribute to developing Guidelines on Policy and Design for innovative health technologies. The topics covered in this group fall into two main areas: 1) Inputs to Policy, and 2) Design and Operation.	15	15	07 Jun 2004 3:22:32 PM by: administrator	
General questions				
Questions about the site Do you have any questions about this site?	1	1	17 Mar 2004 2:25:38 PM by: n/a	

Figure 6: RECKS Discussion Rooms

The main focus of the action research element of the project was therefore concentrated on the HERO project, where we were able to carry out a full action research experiment. This is reported fully in section 3.3 below.

3.3 Action Research with the HERO project

3.3.1 Background

HERO- health and educational support services for the rehabilitation of offenders – is a pan-European research and development (RTD) project funded under the European Commission Information Society Technologies (IST) Programme. HERO developed information and support services (including mental health diagnostic tools; sexual health lifestyle assessment and drugs harm minimisation information) for two groups of prisoners: ‘first timers’ and those about to be released. Its core is an ‘evolving knowledge base’ (called an ‘Interactive Content Repository’). This essentially provides for:

- the collection, classification and categorisation of resources that can be used to develop customised health and learning services for a range of users (prisoners, ex-offenders, prison staff, NGOs etc.)
- tools to edit, add to and enhance these resources
- tools to enable users to find the material most suited to their needs (searching; user profiling; advisor agents)

The ICR is built with a content management system called Inquire2. This provides functions to download, categorise and edit content. The ICR supports a range of content types – from text through to graphics and video clips. But the bulk of the information stored in the ICR is in the form of ‘metadata’, which conforms to ARIADNE standards². Resources are stored in the HERO ICR in a category structure. The category structure is a convenient way of filing the resources in a way that makes sense to the users of HERO, of which there are three main groups:

- ♦ Group 1: offenders (comprising two sub-groups, “first offenders” aged between 18 and 25 years old, typically awaiting sentence or on remand, and prisoners due for release. For these two target groups, HERO aimed to provide two sets of services: health promotion services and learning services).
- ♦ Group 2: prison staff (comprising prison administration staff; educators, medical staff such as doctors, nurses, psychologists, physiotherapists, social services staff, and re-settlement support staff like probation officers).
- ♦ Group 3: service and information providers working for external organisations (comprising Public Administrations and NGOs, providing specialised staff such as trainers, teachers, guidance experts, labour market advisers).

The main needs addressed by these users were identified as follows:

- For young first time offenders – information and support on drugs awareness and harm minimisation; mental health issues (particularly depression, anxiety and drugs rehabilitation); sexual health; fitness and diet; basic skills; how to cope with prison life (bullying; keeping healthy; using time productively).

² ARIADNE is a European standard for e-learning content

- For prisoners about to be released – information and support on: re-adjustment; housing and welfare; staying healthy on the outside (depression; drugs; sexual health); learning and job opportunities
- For professionals – access to state of the art research results; content to develop health and learning programmes; tools to support knowledge exchange and collaborative working

The HERO system was implemented in seven pilot sites, as described in Table 6.

Table 6: Pilot sites

Site	Description
Askham Grange, York, UK	Womens' Open Prison
Deerbolt YOI, UK	Closed 'medium risk' prison for young offenders (age 18-23)
SothA, Erlangen, Germany	Therapeutic Unit for offenders 'in denial'
Chalkida, Athens, Greece	General, maximum security prison
KETHEA, Greece	Centre for just released prisoners, particularly drug-related offences
Athens closed prison	Womens Closed Prison
Centro di Solidarietà (CEIS), Modena, Italy	Therapeutic community for former prisoners and prisoners completing sentences for drug-related offences

Each of the sites represents a particular 'scenario of use' in terms of the overall HERO delivery strategy. HERO as a whole represents a diverse range of settings, user types, user needs and stages in the 'offending life cycle'. The Deerbolt pilot focuses mainly on first time young offenders. In this context, HERO was aimed at: helping young offenders adjust to life inside; providing advice on key choices to be made whilst inside; preparing offenders for re-settlement. In turn, the Erlangen, Chalkida and Athens closed prison sites reflect a longer term, more habitual offending profile, where, typically, breaking the cycle of offending and re-offending is more difficult and more complex. In the case of Erlangen, for example, the HERO services were aimed at inmates who were officially classified as 'in denial' of their offences. Finally, the CEIS and KETHEA pilot sites represent a bridging point between the internal world of the prison and the external world of society. They act as therapeutic communities and 'half way houses' between secure correctional environments and the 'free' world. In these pilots, the emphasis is on rehabilitation and on supporting offenders in their re-adjustment to society.

This diversity is reflected in the different configurations of tools and services provided across the sites, and the underlying pedagogic and health promotion models applied. The services provided by HERO were focused on the one hand on a common 'rehabilitation model' but on the other were customised to reflect these different scenarios of use and configurations of user need. The typical range of tools provided was as follows:

- The Information Repository Database (IRM), including the particular content modules developed for each site

- The IRM management, search and navigation tools, based on a web browser that Allows users to find their way around the content repository and search for particular items
- The User Profiling Tool – builds a picture of user characteristics and needs
- The Advisor agent – uses the User Profiling tool to extract content to match a particular profile
- Discussion Fora – provides spaces to enable users to exchange information, develop their own content and add to the evolving knowledge base
- The interactive game - this modelled decision points and the implications of decisions across the offending life cycle. It presented key decisions and 'critical incidents' at seven levels in the cycle: from sentence, through prison induction, health and learning options whilst 'inside', to preparing for release, and finally decisions around re-settlement. The game presents the implications of these various choices and allows users to access the HERO content repository and chat rooms to acquire information and advice to support their decision-making.
- The HERO visual asset database – a library of video clips (tagged and categorised using ARIADNE standards) which acts as a resource for users to develop their own learning and health content resources.
- The HERO 'How to.....' tool. Like the interactive game, this tool enables users to go through a diagnostic of issues and activities related to a particular stage in the offending life cycle. For evaluation purposes, the tool was used to develop a 'How to survive induction' module. This module took newly-arrived young offenders through a checklist of essential activities (including meetings with health officers, establishing prison visits and so on). The tool provides access to the HERO content repository to enable users to acquire relevant information and advice on each aspect of the induction process.
- Interactive user monitoring' (IUMT) and 'virtual case conferencing' (VCC) tools to facilitate decision support for users (e.g. on learning; sexual behaviours; coping with prison life; coping with release and re-settlement), and promote collaborative working between professionals to support these decisions.

The HERO tools and services are illustrated in Figures 7 to 14. Figure 7 shows the access screen of the HERO website. The seven HERO pilot sites can be accessed by non-registered users as 'virtual drop in centres'. Users can take a virtual tour of each site, visit a prison, communicate with inmates, join a Discussion Group; visit the Video Lounge (containing videoclips of offenders talking about prison life). Figure 8 shows the 'top level' category structure for the Deerbolt Young Offenders Institution. The content is arranged in four meta-categories. The first category is dedicated to staff and professionals. The next three are dedicated to offenders and replicate the three key phases of prison life: Starting your sentence; Doing your time; Release and Re-settlement.



Figure 7 : HERO web portal, providing drop-in access to the virtual pilot sites



Figure 8: Deerbolt Young Offenders Institute Content Category Structure



Figure 9: Deerbolt YOI – sub-categories of ‘Doing Your Time’



Figure 10 : The ‘How to Survive Induction’ tool

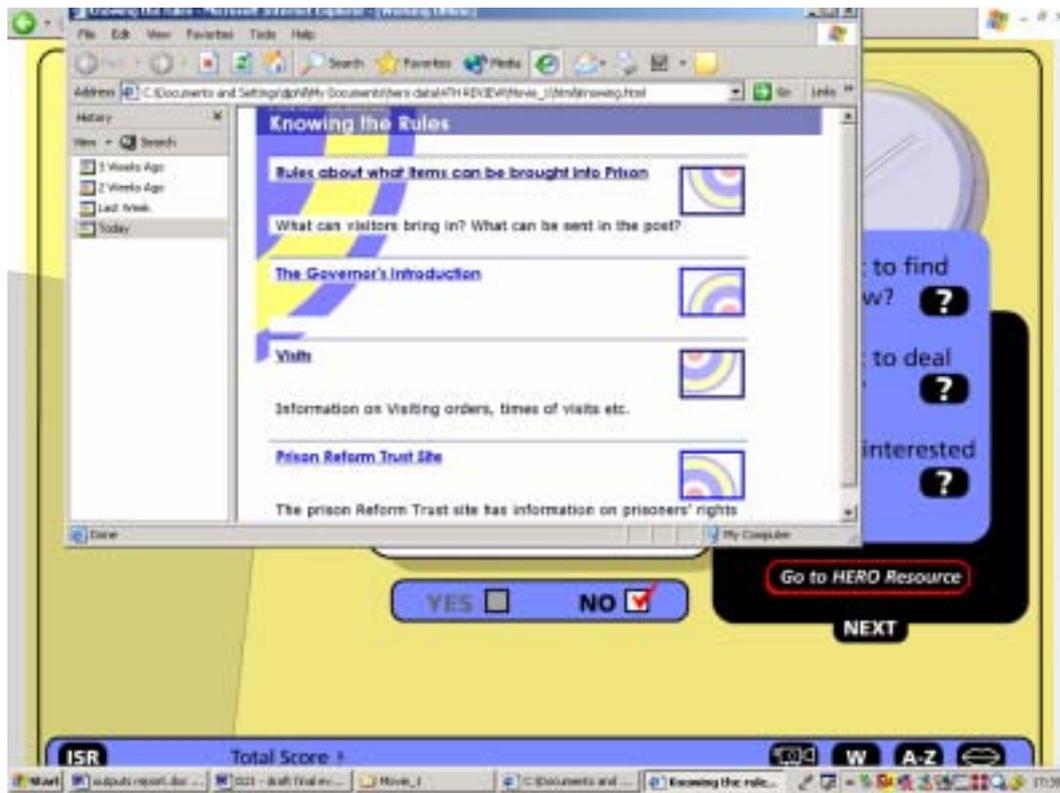


Figure 11: The 'How to Survive Induction' tool: illustration of use of diagnostic data to select content from Repository

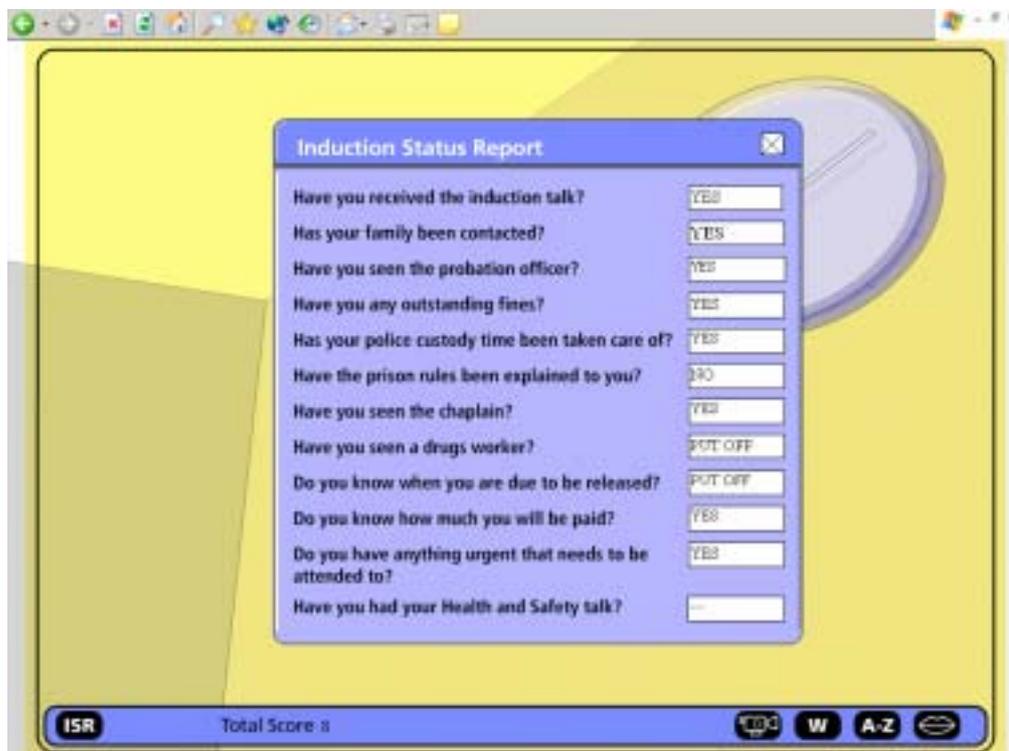


Figure 12 : The 'How to Survive Induction' tool: illustration of outcome of induction diagnostic



Figure 13: HERO Interactive game

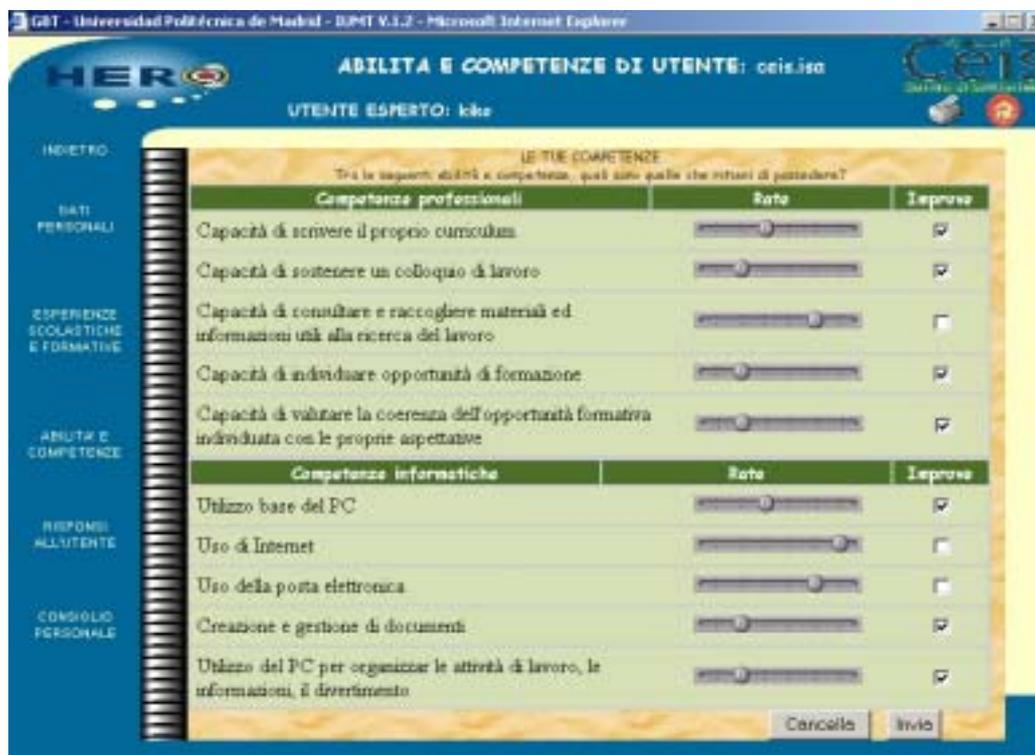


Figure 14: Interactive User Monitoring Tool

Figure 9 shows the next level of the category structure for the Deerbolt site, in this case the sub-categories of content for 'Doing your time'. This meta-

category is sub-divided into six sub-categories that reflect key issues around managing life in prison (for example bullying; offenders who are parents, and so on).

Figures 10 to 12 illustrate the 'How to survive induction' tool. The tool is designed to, firstly, take users through an inventory of the key issues they need to be aware of during the induction phase (for example arranging visiting rights; drugs regulations, and so on). Secondly, the tool provides access to a range of content located within the HERO Repository that allows users to explore some of the issues around Induction. For example, depending on the user's answers, the tool provides content on bullying, literature on drugs and sexual health, and so on. Users can also access decision support tools – the A to Z of Mental health; the 'Talk to Someone (ask and expert)'; 'True Stories' (providing access to relevant film clips in the video library). Thirdly, the tool provides a checklist which identifies areas of the induction process that need to be managed and followed up

Figure 13 illustrates the interactive game. The game simulates seven 'levels' of the 'offending life cycle' – from sentence to re-settlement. Users can select an avatar (character) who represents a particular configuration of attributes (for example prison hard man; 'keep your nose clean', and so). The characters provide simulations of possible outcomes associated with key decision points in the life cycle (e.g. whether to take a drugs rehabilitation course). Tasks also represent typical prison life scenarios and create opportunities for learning. For example, one task is to make the Governer a sandwich. The user has to select the correct ingredients and information is provided from the HERO Repository on, for example, nutritional aspects of different ingredients. In addition, information on how to become a chef is also provided.

Figure 14 shows the interactive user monitoring tool, configured for the CEIS pilot site in Bologna. As described above, the IUMT is a web based tool that capture quantitative and ethnographic data about the users at the HERO pilots. The tool collects data in the form of segments of information – or 'tabs' – that respond to specified clinical and lifestyle markers – for example diet; self-rated mood and so on. Another data capture schedule collects similar data on skills profiles and learning needs. Data can be ported to an adapted form of an electronic patient record (EPR) and a skills record to enable collaborative case conferencing to take place between professionals, using the IUMT data as input, and linked to the virtual case conferencing tool (VCC). This uses a Discussion Forum as a generic platform to develop a collaborative information exchange between professionals, and a supporting medium for on-line case conferencing. The on-line Forum allows the sharing of information between support providers through discussion groups.

3.3.2 RECKS input to HERO

RECKS provided inputs to the HERO project in two ways:

- Providing inputs to the continuing evolution and refinement of the HERO tools and services
- Designing and implementing a specific action research experiment, involving the setting up of an additional pilot site.

i) Inputs to ongoing evolution of HERO

The formative inputs (contributing to the ongoing development of tools and services) provided by RECKS were developed from a synthesis of the results of the RECKS review of state of the art (review of literature; audit of collaborative knowledge systems) and the results emerging from the intensive case studies. The results synthesis focused on the following main areas: what had been learned on theory and practices around motivation; the effect of organisational and institutional arrangements on information and support delivery; usability factors; utilisation factors ('what worked, for whom and under what circumstances).

The engagement approach (i.e. knowledge transfer mechanisms) between the RECKS and HERO projects was based on monitoring and review (regular workshops between HERO partners and the RECKS research team). The main outcomes of this ongoing engagement can be summarised as follows:

- Re-design of the HERO web site, including a more effective and user-friendly user interface
- Review and updating of the content in the Interactive Content Repository
- Diagnostic and assessment tools to enable a 'skills audit' and a 'health audit' to be carried out for individual prisoners. These provide input to a learning and health plan, progress of which can be monitored via the IUMT and VCC
- Re-design of the HERO Discussion Forum and video library to create 'Video Lounge' and 'Talking Shop' which enable users to 'step into the shoes' of each other (for example through prisoner-public dialogue; professional-professional debates and so on).

ii) Action research pilot site: 'One Spirit'

However, the most significant enhancement to the HERO system was the addition of a new pilot site – One Spirit – to serve as the RECKS action research host. The pilot involved collaboration with a number of partners in London – including the 'One Spirit' project, Hackney Young Offending Team, Hackney Music Development Trust and the European Business School.

The 'One Spirit' pilot site was seen as an opportunity to 'close' the circle of offending by bridging what might be described as the two 'extremes' of a 'life of crime'. In this case, the user group targeted was comprised of young

people (12-18 years) who have an 'offending history'. In some cases, they have not been convicted of an offence but are designated 'at risk' of offending. In other cases, the courts have decided they should not be sent to a secure environment, but they are required to report to a case worker delegated by the Youth Offending Team (YOT). A key objective in this pilot site was to raise awareness among the participating young people of the possible implications of offending. It therefore included collaboration with prisoners on 'Death Row', San Quentin, California. The One Spirit pilot was designed to reflect, unpack and validate some of the key conclusions that had been learned through the RECKS research activities. The key conclusions (hypotheses) incorporated in the design of the new pilot were as follows:

- Collaborative knowledge systems need to simulate and interface with communicative practices that reflect real 'life-world' experiences of participants (for example, as the RECKS 'audit of systems and services' showed, health promotion and health support 'messages' work best when supported by 'holding techniques' that precipitate and retain interest. These techniques work best when they can be applied in the users' day to day life)
- The most powerful forms of collaborative knowledge production occur when new knowledge emerges as a result of synthesis between different (and frequently opposing) constructions of reality. These constructions occupy different mediations: they can be mediated through different life experiences (and different life worlds); different professional constituencies; different 'communities of practice', and different ontological and theoretical positions. This means that collaborators need to exchange life histories ('life swapping') rather than simple information (at a basic level, an example in digital health systems is the use of 'True Stories' – video clips of what it is like to live with Alzheimers, for instance)
- Digital health information and support systems have to be integrated within an underlying pedagogic model. This pedagogic model needs to be consistent with the configuration of user profiles, user needs, scenario of use and organisational arrangements of the system and service being delivered. Since collaborative knowledge production embodies 'lifeworld' exchanges and 'life swapping', transmissive (i.e. conventional expert-consumer) learning models are likely to be unsuitable for all but the most basic forms of information dissemination systems. Constructivist approaches are likely to be more appropriate.
- In turn, the adoption of a constructivist pedagogic approach implies the active involvement of 'users' both in the design of the system (across the full range of functionalities – content; interfacing; delivery; organisational arrangements) and in the co-production of content.

In this context, the 'One Spirit' design incorporated a number of features intended to operationalise these key conclusions. One unique feature was to create an environment in which users – young people 'at risk' of offending – were put in touch with inmates on 'Death Row', in San Quentin, California. The Death Row inmates can be thought of as representing one extreme, and catastrophic, end-point of a range of options, choices and life trajectories associated with an 'offending life cycle'. Participating inmates on Death Row

corresponded by letters with the One Spirit participants, discussing the circumstances that had led to their ending up on Death Row – invariably drug-related - and the choices they had made. An example of part of this correspondence is shown in Figure 19. As a result of this collaboration, the One Spirit young people were able to an extent to ‘step into the shoes’ of their correspondents. This collaboration then generated group discussions between the One Spirit participants, and formed the basis of inter-group collaboration on a set of musical compositions, and a film.

Music composition – focusing on rap and R&B – singing and film-making were thus used as ‘holding techniques’ through which to promote collaborative knowledge production and learning. These genre were selected specifically to reflect the interests of the participants, and more importantly, the cultural discourses and communicative practices of the ‘life world’ with which the young people engaged – a predominantly black East London community.

More broadly, the pilot reflects a particular application of the RECKS ‘blended’ e-health and e-learning model to the HERO project. This is illustrated in Figures 15 to 17. Figure 15 shows the adaptation of the results drawn from two of the RECKS main research activities: the review of state of the art, and the audit of systems and applications, to the analysis of user needs and scenarios of use carried out in the HERO project. From the user needs analysis, the key barriers to delivering health promotion and support services to the HERO target users were compiled. These were then linked to an assessment of ‘what works’ (drawn from the generic results of the RECKS review of state of the art, and from a review of health promotion and support services in the criminal justice domain). This analysis of ‘needs-desired outcomes’ are filtered through two sets of conceptual paradigms: one based on ‘collaborative knowledge’ (incorporating theories of learning; types of learning; types of knowledge and theories of empowerment) and the other based on ‘health promotion and support’ (incorporating health promotion paradigms; theories of behaviour change; models of health support). This produces a set of practical aims intended to act as a checklist to design the collaboration model, delivery strategy and content structure for the HERO project.

The checklist is further expanded in Figure 16. This links the broad health promotion and support model to, firstly, a set of ‘hypotheses’ about what is likely to work; secondly a set of specific health needs that need to be addressed; thirdly, the types of resources through which these needs are addressed; fourthly, the desired outputs associated with the resources, and finally, the desired outcomes.

Figure 15: RECKS Health Promotion and Support model applied to HERO

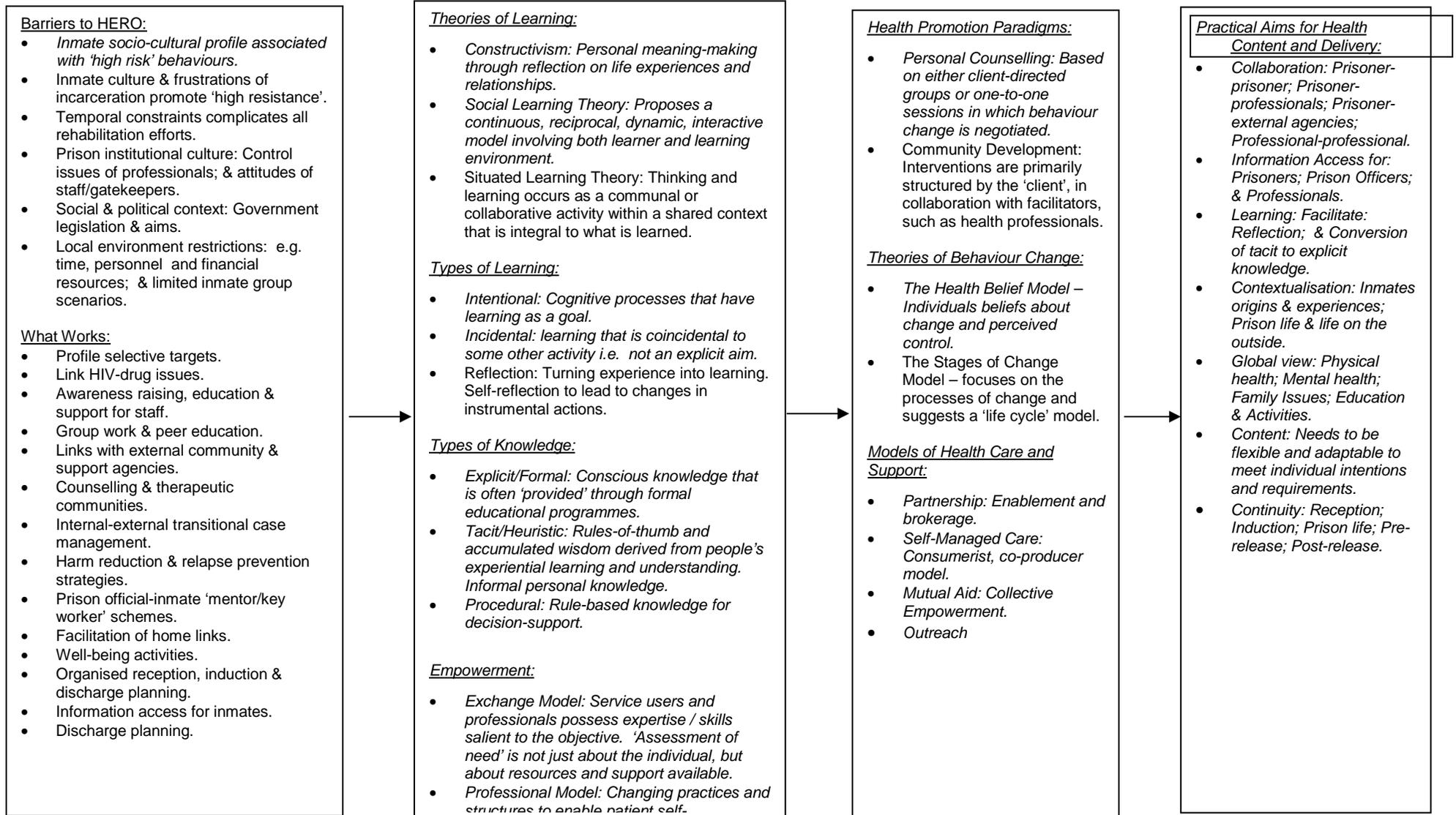


Figure 16: Linking Theory and Assessment Needs to Content

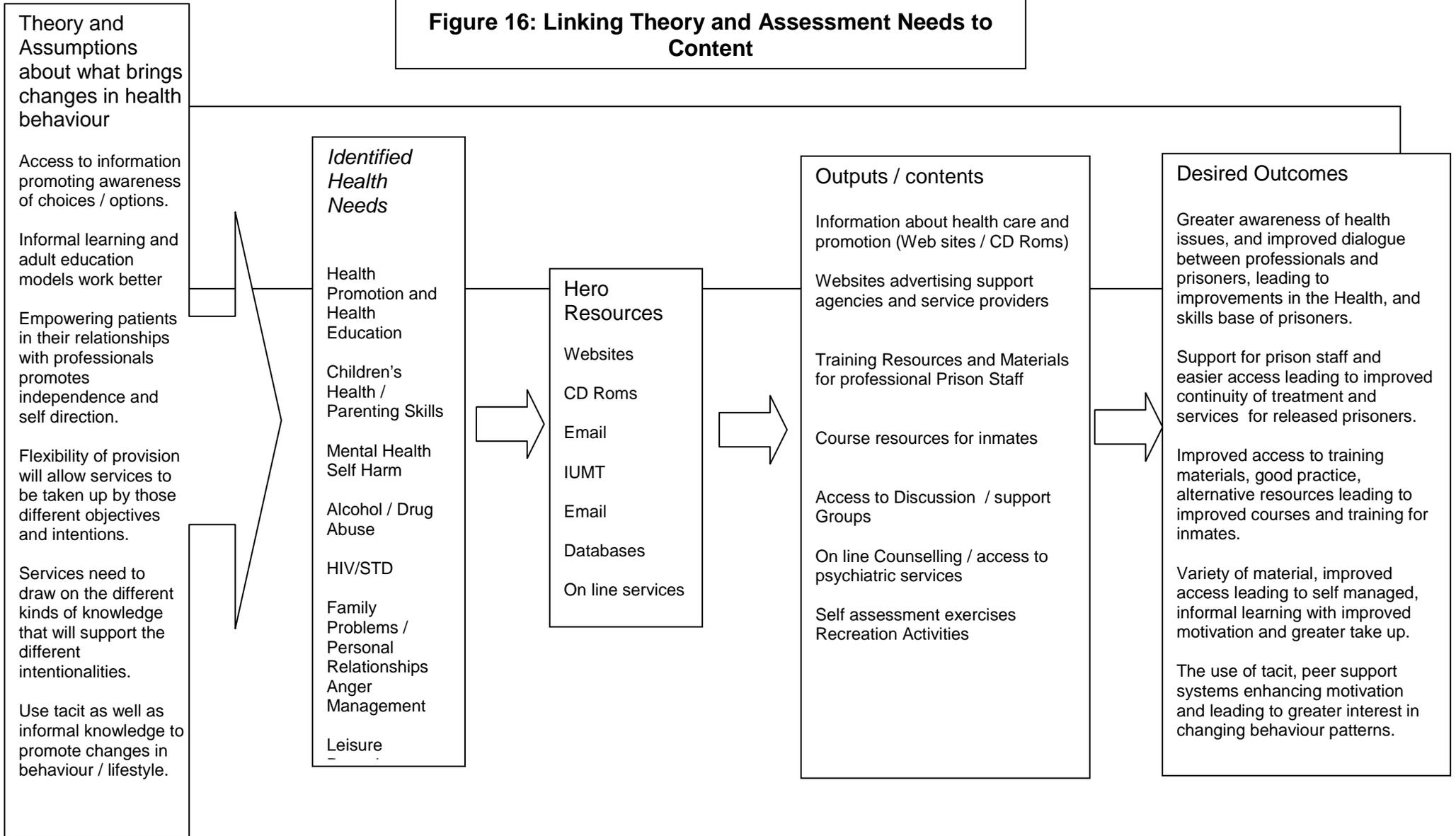


Figure 17: One Spirit Structure

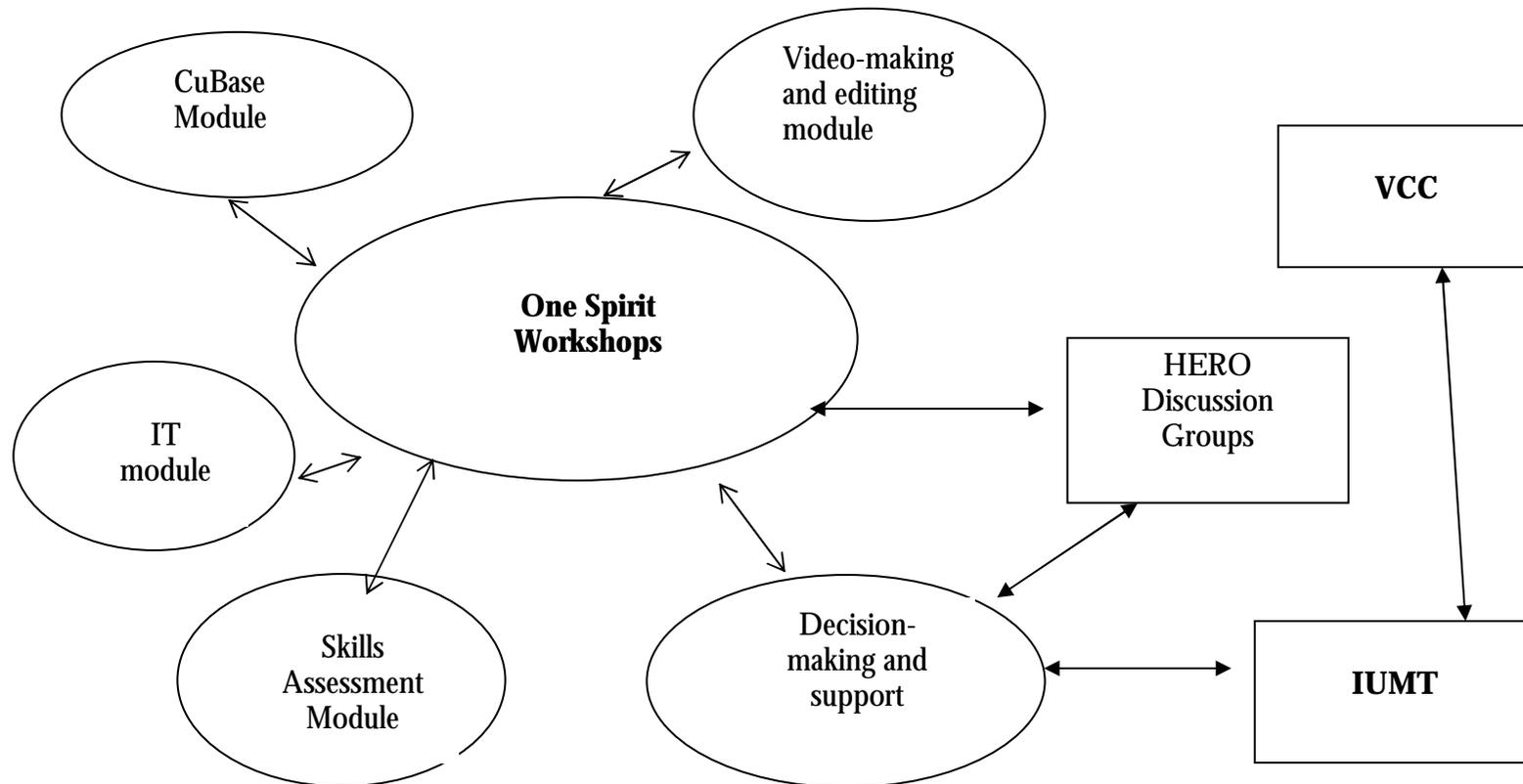


Figure 17 shows how this model was implemented in practice in the action research pilot site, and how the site was integrated within the HERO system. The model has at its core the One Spirit vocal training workshops. The 'direct learning' promoted by the voice training, musical composition and song-writing activities implemented through the workshops was supported by additional activities provided through the HERO platform and tools. The blended environment was intended to enable participants to essentially 're-invent' themselves through: 'life swapping'; practical immersion in a creative and collaborative environment, and through 'learning by doing'. To some extent, the underlying conceptual approach here mirrors Foucault's notion of re-discovering 'techniques of self-mastery' – as discussed above in section 2 (Figure 20). Six self-contained support modules were provided within the overall learning environment and setting of the workshops, and targeted directly at the participants themselves (i.e. clients referred by the Hackney YOT). These are as follows:

- CuBase module – a self-directed and self-managed course in using music composition, editing and recording software.
- IT module - a self-directed and self-managed course to develop IT skills (standard software packages; web design)
- Video-making and editing module – an interactive course, supported by a tutor, in shooting video, and using editing software like 'Director'. Participants were encouraged to use these skills to develop a 'visual ethnography' of the whole experience
- Skills assessment module – this used HERO tools (the skills assessment features and interactive user monitoring tool) to get the participants to de-construct and re-construct the skills they were learning in the workshops, and the tacit and formal knowledge they already have, in order to map out some possible future learning and career strategies.
- Personal health check – this enabled users to go through a diagnostic checklist of self-reported rating scales on three dimensions: sexual health and STD minimisation; drugs awareness and harm minimisation; mental health (self-esteem; social relationships depression)
- Decision-making and support services – this bundled a range of HERO tools and services: the HERO Content Repository; the HERO decision support tools; the 'A to Z' mental health support system; the 'Ask an Expert' tool, and the Chat Line features, to enable participants to explore some of the issues that emerged over the pilot (on offending; on learning; on health) as they took part in the project.

In addition, the HERO Content Repository and Discussion Groups were also provided on line to enable the professionals involved in the project to access the resources in the HERO system; collaborate with each other; and collaborate with the HERO experts in the partner institutions in Greece, Italy, Spain and Germany.

A key feature of the One Spirit pilot was the integration of the Interactive User Monitoring (IUMT) Virtual Case Conferencing (VCC) tool. As illustrated in Figure 18, the IUMT was re-designed for the purposes of the 'One Spirit'

experiment: firstly, to contextualise the tool from its Italian context to its London context; secondly, to integrate the tool within the overall pedagogic model (with its emphasis on creativity). The re-designed IUMT incorporated personal health and skills assessment diagnostics, both with an emphasis on the factors that were identified in the user needs assessment as highly correlated with risk of offending (low self-esteem; anxiety; drugs-related behaviours). Outcome data from the diagnostics were uploaded to a 'Health and Learning Plan', personalised for each user. The data in the 'Health and Learning Plan' were deployed as follows:

- For 'One Spirit' participants (i.e. the young people 'at risk'), the diagnostics were used by the system advisor agent to construct a personal portfolio of resources, customised to the needs of the particular user. These resources were then downloaded from the HERO Content Repository (using the Advisor Agent) for access by the user.
- For Youth Offending Team Workers, the Plans were used as the basis to monitor progress on an individual case as the One Spirit Programme progressed. The VCC also enabled YOT workers to communicate with each other to manage the case.

For 'triangulation' purposes, the re-designed IUMT as deployed in the Hackney scenario of use was compared against the results of the tool's use in the CEIS environment (Italy).

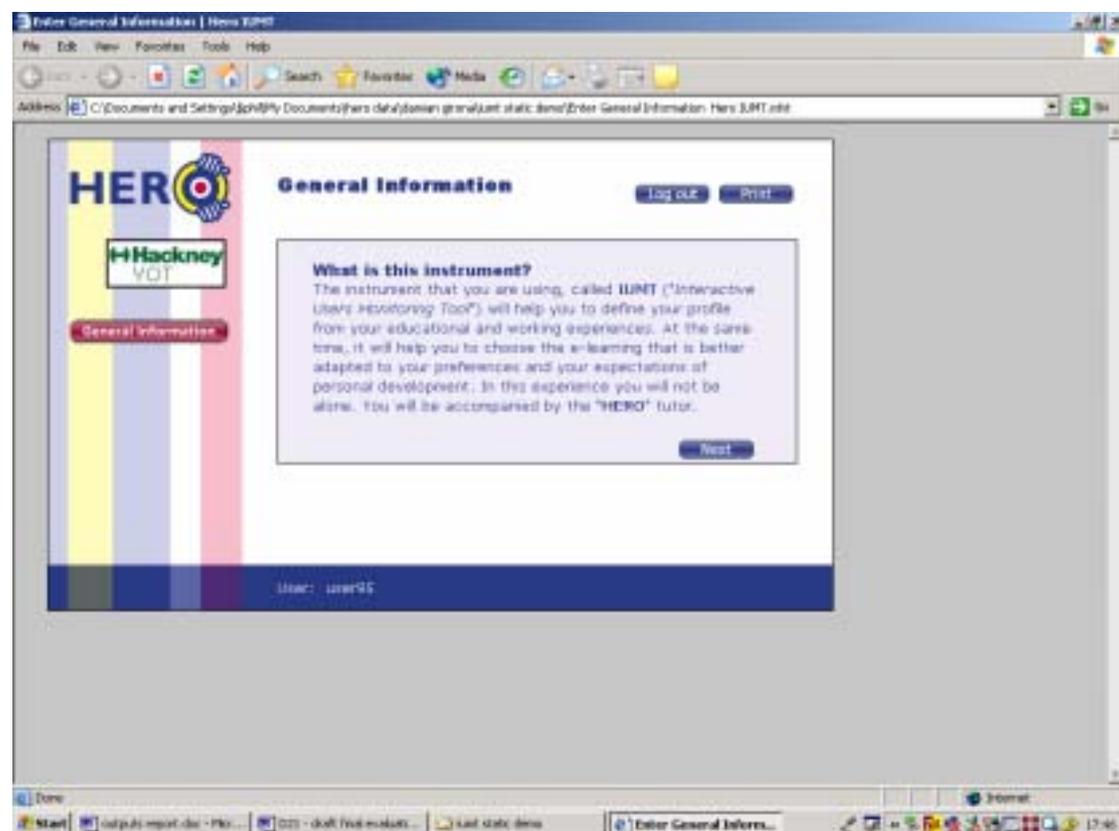


Figure 18: IUMT re-designed for 'One Spirit'

Currently I am on Death Row at San Quentin State Prison in California charged with three murders. Murder for hire, Murder Robbery and Murder of an informant, I also have an additional sentence of 25 to life for Conspiracy to Commit murder

So what happened? This leads me back to the question I posed earlier... "How DOES SOMEONE END UP IN THIS SITUATION?" CHOICES! Each one of us makes CHOICES on a daily basis throughout our life that effect our life and the lives of others and influence the

Figure 19: Example of correspondence with Death Row inmate



Figure 20: 'Re-invention of the self' – acquiring 'techniques of self-mastery'

3.3.3 Results of the action research

3.3.3.1 Implementation

The 'One Spirit' action research was carried out over a period of 4 months (from November 2003 to February 2004). A total of fourteen young people participated in the Programme. It was delivered through a series of weekly workshops (around 5 hours duration). Twelve professional staff were deployed on the programme (comprising specialist tutors – singing, film-making, IT - research staff; management staff; social and probation workers).

Evaluation data were collected to monitor process, outputs and outcomes of the Programme. These data are summarised in Table 7.

Table 7: One Spirit Evaluation Data

	Number
Pre-test SAQ	14
Post-test SAQ	14
Observation	12
Focus Groups	240
Interviews	11
TOTAL	291

A pre-test/post test questionnaire was administered to the young people participating in the Programme. The pre-test questionnaire covered: personal and demographic data; offending history; educational and skills data; health data; expectations. The post-test questionnaire covered self-reported outcomes.

The data shown for Focus Groups represents the number of participants involved in the group times the number of occasions on which the groups were implemented. So in the case of One Spirit, focus groups were implemented with all participants on a regular basis as part of the feedback session associated with delivering HERO services. Ten focus groups were implemented with 12 participating users and ten with 12 participating staff at each of the ten weekly workshops carried out by 'One Spirit'. The focus groups concentrated on: process factors (how the Programme was being delivered and how it could be improved) and perceived benefits.

The data for observations represents the number of times an observation analysis was carried out (rather than the number of users being observed). The observations were carried out using a pre-designed template to cover: personal and social interactions; technology utilisation patterns; learning behaviours.

The interviews were carried out post-experiment with the professional staff, focusing on: perceived outcomes; problems and issues.

3.3.3.2 Outcomes and Impacts

i) Overview

It is necessary to distinguish between ‘short term’ and ‘intermediate’ impacts – for example what happened during the implementation of the action research– and longer-term impacts, such as the effects of HERO on subsequent offending patterns of the ‘at risk’ young people, which is beyond the scope of our action research experiment and its evaluation. Within the Programme, HERO was able to offer young people the possibility to, firstly, step into ‘extreme offenders’ shoes – via communication with inmates on Death Row at San Quentin prison, and therefore visualise the ultimate possible consequences of a ‘life of crime – and, perhaps more importantly, it was able to offer the participants alternatives to offending. The ‘health’ dimension of these ‘alternative’ futures focused on: providing a diagnostic of the key health-related factors influencing offending behaviours (drugs use; depression; anxiety; social relations and interactions), and on providing content (‘true stories’; videoclips; text; website links) to explore these issues. With regard to the ‘learning’ dimension, it offered ‘life chances’ through tuition in music, video and IT skills; through providing access to customised services aimed at and through skills assessment and follow up.

Table 8 shows the impacts on self-development associated with the information and support services provided, as measured by self-reported rating on a range of dimensions by the participating young people.

Table 8: One Spirit: User self-rating of impacts on personal development

Number of Users	<i>No/slight improvement</i>	<i>Strong improvement</i>
Improved your confidence	3	9
Improved your social skills	3	9
Helped you to meet people	6	6
Helped you to make friends	2	10
Improved your general knowledge	6	6
Improved your knowledge about particular subjects	0	12
Improved your qualifications	0	12
Improved your writing or reading skills	10	2
Contributed to improving your job prospects	8	4
Made you want to find out about further training or educational courses	5	7
Made you make any changes to your job or career plans	10	2

The data shown in Table 8 illustrate a number of key findings of the One Spirit pilot. The strongest impacts have been in relation to developing technical skills (for example in film, photography and musical skills). Participants also reported significant improvements in transferable (‘soft’) skills - for example in team working and communication skills. This suggests that the constructivist model used to deliver the Programme was effective in stimulating a ‘climate of collaboration’. This climate would in turn appear to have had an effect on ‘self-re-invention’, as measured in terms of personal development indicators. In the

light of the evidence, from the user needs analysis, that a key characteristic of the young and at risk offending profile is low self-esteem and poor social skills, the results show a major improvement in these areas. It is also significant that the majority of users reported that the experience had made them want to find out about further educational opportunities, and all the users said they had improved their knowledge. However, it should be noted that impacts in terms of direct health-related outcomes (for example reduction in drug use) were not identified through the evaluation data.

The following observations from young people and staff reinforce these conclusions:

"The information was an inspiration and made me think differently about life".

"I think that (Death Row) it's a hard place to be in and it made me think more not to do bad things because you could end up in these situations".

"One Spirit meant having to do something exciting, interesting and learning new things on a Saturday rather than doing nothing",

One Spirit Young People.

"What I think these young people value the most are people taking an interest in them. To believe in them and to be consistent. Also, to be given opportunities and responsibilities that they may not normally be privy to. Initially there were barriers. It took a while for them to start getting involved. Maybe the trust wasn't there yet. The beginning of the session went quite slowly until they started to pick up. We had to work hard to keep them interested and involved. I feel this changed once they heard and read about the Death Row element to the project. A very useful discussion followed that presentation. After that it seemed there was purpose. Songs were written and nearly completed that day. They became really engaged after that."

"Many of them suffer from low self-esteem and lack of confidence. That self-esteem has risen over the past few weeks. It has been interesting seeing even the very shy, come forward and make suggestions that may have the potential to thrust them into the spotlight"

"I have learned a great deal from the kids. Their lives are so far removed from my own, yet they have passion, intelligence, tenderness and a whole lot of talent. It's been an education seeing that and a blow to any stereotypes I once held on to".

Staff, One Spirit

ii) Impact of collaborative knowledge tools

The Interactive User Monitoring Tool was considered to be well-designed when tested at the CEIS site, in Italy, but was found to be of limited utility. This was for the following reasons. Firstly, the tool did not add significant value to the support services being offered in the Centre. In terms of health support, CEIS's programme was based mainly on peer support and group therapy, and the individual-focused and contingency based model used in the tool was not consistent with this regime. Secondly, the skills assessment functionalities were limited in scope and range, focusing primarily on technical skills. Thirdly, there was no effective bridging between the outputs of the IUMT and the virtual case conference tool. On the one hand, insufficient staffing resources were allocated to promoting collaborative working. On the other, the learning outcomes suggested by the skills diagnosis could not be followed up in terms of re-settlement strategies, because there was no linkage with external service organisations, such as job placement agencies, or welfare services.

In the One Spirit case, the health diagnostic tools and support services were considered to be of peripheral value in **direct** terms. As noted in the preceding section, the skills assessment and Learning Plan functionalities were considered to be of far more practical value, and more directly translatable to rehabilitation strategies and desired outcomes. The main health benefits associated with participation in the One Spirit Programme were **indirect** rather than direct. Participants did access the Repository to explore issues around drugs, for example, but this was done in a haphazard and unsystematic way. Similarly, mental health benefits associated with participation can perhaps best be seen as 'incidental'. They were part of a 'package' of benefits associated with the Programme as a whole and would appear to be related to factors such as: increase in social interaction and team-working, linked to improvements in self-esteem, linked to a reduction in 'at risk' behaviours (for example drugs-related activity; gang violence). This is illustrated by anecdotal evidence derived from the focus groups, which tended to point to technical and skills-related outcomes as the main benefits derived from the Programme.

The data derived from the evaluation of the IUMT and VCC in the One Spirit pilot indicates that knowledge sharing has had a degree of impact not just on the technical skills developed over the course of the pilot, but in terms of getting users to think about their social and personal behaviours. As one member of staff observed:

"Kids have already asked when the next pilot is running and would like to play a part in facilitating this. We have proved that we can keep kids engaged and in running this project in other boroughs, it starts to break down barriers and territorial issues experienced on the street, through gangs and so on"

However, the introduction of collaborative knowledge systems had only a minimal effect in terms of promoting greater inter-professional working and

developing integrated 'communities of practice'. This would appear to be related to a number of factors:

- Staff resistance; low motivation and lack of time. In view of these factors, the presence of a 'product champion' is essential for successful buying into collaborative systems.
- Staff resistance is in turn linked to a lack of cross-boundary working. Professionals tend to operate in their own 'sectoral silos' (health; training; throughcare and so on). On the one hand, they fear that the introduction of new technologies will undermine their role and status. On the other, they are resistant to inter-sectoral collaboration. This was a major reason why the IUMT and VCC were of limited effectiveness.
- The typical information and knowledge seeking behaviour pattern of users is instrumental rather than exploratory. Most users appear to use IST technologies in a goal-directed way, rather than to explore new ways of thinking.
- Lack of investment – discussion groups require moderation. The limited administrative and support resources provided to the project by the Young Offending Team precluded the implementation of exploratory collaborative learning, which required staff to act as moderators and managers of information flows.

iii) RECKS value-added

As noted in section 3.1 above, the main aims of the action research work package, as specified in the workplan, were:

- To extend the results of the case study research by actively involving users in developing and evaluating enhancements to the collaborative knowledge production systems used to deliver health information and support
- To add practical value to the existing systems being researched

It is difficult to quantify – or even qualify – the practical added value derived from the migration of learning acquired in the RECKS project to developing and enhancing the HERO tools and services via the action research activities. Table 9 shows a comparison of 'One Spirit' outcomes vis a vis the other HERO pilot sites in relation to three indicators:

- % of participants reporting they had gained some benefit from participation
- % of participants reporting they had used some of the benefits from participation in a real life
- % of participants reporting that participation had led to some activity (for example change in lifestyle; further education)

Table 9: RECKS effect on rehabilitation

	% gained benefit	% used in daily life	% led to activity
Askham Open Prison	72	52	36
Deerbolt YOI	56	48	18
SothA therapeutic	N.A.	N.A.	N.A.
Chalkidas max security	N.A.	N.A.	N.A.
Athens Womens Prison	62	74	75
KETHEA therapeutic	71	43	42
CEIS therapeutic	22	18	12
One Spirit	84	65	42

As Table 9 shows, 84% of ‘One Spirit’ participants reported gaining some benefit – a significantly higher proportion than in the other sites. Similarly 65% of One Spirit participants reported they had used some of the benefits from participation in a real life – the second highest total compared to other sites. This would imply a direct gain in the effectiveness of the tools and services deployed in HERO as a result of the migration of knowledge and learning from RECKS. This observation is supported by the anecdotal evidence derived from the analysis of the action research experiment, as reported in the preceding section. However, a number of qualifying factors need to be taken into consideration:

- The small base of the population frame – only fourteen young people participated in ‘One Spirit’
- The particular idiosyncracies of the domain in which the action research took place – the offender rehabilitation environment is by no means a typical domain for the design and delivery of digital health promotion and health support services.
- The variability of the domain – the HERO pilot sites reflect a wide range of offending and rehabilitation environments. Indeed, in the majority of the sites – particularly the high security prisons involved in HERO – severe restrictions were imposed on the technology that would be permitted. This restricted scope for interactivity and the deployment of collaborative knowledge systems.
- The subordinate value attributed to and attention directed towards the ‘health’ aspect of rehabilitation compared with the ‘learning and skills’ aspect by the managers of the pilot sites.

Nevertheless, the action research experiment was, on balance, successful in terms of developing and implementing an effective model for promoting collaborative knowledge production. In turn, it offered valuable insights into how these systems worked and how they can be improved. These insights provided an input into the final conclusions and recommendations of the project, which are discussed in the next Section.

SECTION 4: Policy Framework, Recommendations and Design Principles

4.1 Introduction

This Section covers the final objective of the project:

- to produce good practice guidelines and policy recommendations, and disseminate the results of the project to appropriate stakeholders

It draws together and synthesises the main conclusions of the project and applies them to two sets of practical outputs: a policy framework and recommendations to promote the development and implementation of digital collaborative health information systems and support services, and good practice guidelines for the design of effective systems and services. The framework, recommendations and design principles are derived from:

- The conclusions of the 'state of the art' review (literature and practice review; expert panel interviews; audit of systems and services)
- The results of the intensive case studies
- The results of the action research
- The project dissemination workshops
- The RECKS on-line Discussion Forum (which mirrored and supported the workshop format)

4.2 Main results and conclusions of the project

The need and demand for collaborative health technologies

The main conclusion to be drawn from the results of the project – and the starting position for policy recommendations and design principles – is this:

Collaborative knowledge systems and services make up a very small proportion of the range of health technologies currently available on the market, and under development through European Commission and domestic research and development programmes.

As the 'Audit' showed, only 4% of the health technologies available on the UK market and 7% of EU RTD in health technology programmes focus on collaborative knowledge production.

A supplementary conclusion is:

Those collaborative knowledge systems and services that are on the market, or under development, generally exhibit a low level of sophistication and interactivity. The majority are in fact basic dissemination systems providing 'top-down' information services using a conventional 'transmissive' (expert to consumer) model.

The results of the 'audit of systems and services' showed that 57% of the systems covered by the audit were classified as 'transmissive'. In these cases, the knowledge creation, knowledge-sharing and learning approaches underpinning the system adopt a traditional didactic form of interaction. Users act as passive consumers of information provided by experts and professionals. There are some functionalities built into the system to promote 'user involvement' but these functions are primarily tokenistic.

These conclusions beg the questions:

- does the UK national health system need these systems and services?
- Are they useful, particularly within the context of current health policy?

The current policy rhetoric, agenda and instruments (as described in the RECKS project Report 'Collaborative Knowledge Systems in health promotion and health support: Review of State of the Art') suggests an affirmative answer to both of these questions. Our assessment of the health policy environment highlights a raft of policy initiatives aimed at 'empowering' citizens and patients in the UK (and more widely within the EU). These policies have been aimed primarily at 'putting information to work' in order to improve the effectiveness and efficiency of the NHS and ultimately the health of the nation. The 1998 policy document 'Information for Health', for example, proposes a number of initiatives – lifelong Electronic Patient Records (EPR) for every citizen; instant access to patient data and 'evidence-based practice'; on-line public access to health information, through NHS On-line and Digital Interactive Television – each intended to promote the 'information society for all' with regard to healthcare. The current policy context for healthcare implies a substantial paradigm shift in the ways in which different stakeholders – especially health professionals and lay people – communicate. New policy initiatives are aimed at the decentralisation of healthcare from acute to primary and self-managed service delivery. They place more emphasis on health promotion and disease prevention. They imply a movement away from the 'consultant-driven' model and towards more 'power-sharing', and the involvement of health practitioners and patients in new partnerships. High level policy drivers include new legislation to take forward patient/citizen empowerment agenda. Examples are the Health and Social Care Act 2001 and the NHS Reform Act 2002. This can be set against the broader policy background of 'joined up government' – for example the integration of patient-centred health within an over-arching framework of 'e-government', and its place within the Government's vision of communications integration,

illustrated by the recent creation of the Office of the e-Envoy.³ Joined up government in turn resonates with images of 'empowered citizens', social capital and active citizenship.

Key health benefits

The project results identify a range of positive outcomes associated with the use of digital collaborative health information and support systems:

- The most significant benefits are for people with a health condition. Collaborative knowledge systems and services can support health management and illness coping; reduce feelings and anxieties around 'isolation'; provide inputs to decision-making and therapy choices.
- There is some evidence that collaborative knowledge systems and services address some of the dynamics that contribute to 'health exclusion'. They provide access to information and support services that are not usually catered for by mainstream delivery. Important examples include: people with mobility problems; lone parents; people suffering from chronic illness
- For health professionals, the main benefits are associated with: access to state of the art and latest research results and good practices; opportunities for knowledge development through networking; inputs to Continuing Professional Development; improving the effectiveness of client handling (for example through the use of integrated electronic patient records and discussion groups).
- There is some evidence that using these systems and services can lead to 'multiplier effects' (for example finding a new job through expanding social and professional networks).

So, on the surface, there is a clear policy imperative for these systems, and some evidence from the RECKS project that they do provide tangible benefits.

4.3 Policy Framework

But whether they are useful or not depends on whether 'information' or 'knowledge' is perceived as the significant currency in policy circles.

For example, there was one view amongst the experts consulted in the project that patient empowerment is a rhetorical form of risk management, a way of shifting the spotlight – and the blame for service delivery failings - from professionals to patients. Giving patients and citizens 'informed choice' gets professionals off the hook.

An alternative view is that policy is now very centralist, and technology can be used for dissemination, knowledge creation and empowerment in more anarchic or democratic ways. However, on the ground, citizen empowerment is not a concept with many adherents. As our case study on the 'digital value

³ In, for example, the DTI White Paper 'A New Future for Communications', 2000

chain' demonstrated, health agendas, and consumption patterns, are set by alliances of communications companies, pharmaceutical and health-related business, consulting groups and policy makers – not by citizens or grass roots professionals.

This perspective is supported by the outcomes of our 'audit of systems and services' and the resultant 'dual typology' that was derived from the audit. This demonstrated that the dominant paradigm – the 'cultural logic' – of collaborative knowledge systems in the health domain is firmly instrumentalist. There is space, and opportunity for 'discursive' types of collaborative knowledge systems that can operate in territories of 'marginal practices', and which promote 'techniques of self-mastery' (to use Foucault's terms) but there is no evidence of a grass roots movement towards developing these territories – nor is there much evidence of a 'general will' or public groundswell of demand. Indeed, as our thematic case study showed, a number of examples of effective 'dialogic' and 'reflexive' collaborations in the healthcare domain were not supported by technology.

In other words, a key conclusion from our study is that the policy, political and socio-cultural environment surrounding health technologies is highly volatile, turbulent and contested.

At least three broad dynamics that are driving this turbulence can be identified:

The Integration Dynamic is being driven, at least on the surface, by government policies and rhetoric aimed at 'informed choice' and citizen empowerment. These are underpinned by an infrastructure based on the e-Government Interoperability Framework (GIF) which envisages that all key government services should be available electronically by the year 2005, over a wide variety of channels, including Digital Interactive TV. The 'intelligent network' created will provide the basis for the seamless integration of information services, stimulating demand-led markets, new forms of competition and collaboration and a corresponding increase in public access to information and services, and, subsequently, better informed, knowledge driven self-management of health .

The hegemonic dynamic envisages a primarily market-driven and expert-driven diffusion trajectory for health technologies. It is shaped primarily by differences in the political and administrative structures of healthcare systems in Europe, and the development of powerful agenda-setting alliances between communications companies, pharmaceutical and health-related business, consulting groups and policy makers. This gives rise to opportunistic niche markets developed by alliance partners; greater autonomy given to hospital administrators and primary care 'fund holders' in the delivery of health care, and the maintenance of a relative status quo in the current hierarchical organisational structure of healthcare. This process is driven by new institutional arrangements (PPPs) based on value-chain funding models.

These new partnerships entail some organisational re-engineering. This focuses mainly on the devolution of responsibilities to primary care providers as referral 'gatekeepers', and the broadening of delivery care roles amongst a wider group of service providers, for example nurse practitioners and paramedics. Health informatics products and services are primarily focused on facilitating networking between specialists and GPs, and an emphasis on the utilisation of telematics systems for clinician decision support, practice management and teletraining. DiTV systems are used primarily as gatekeeping mechanisms to bundle packages of products and services for consumers, using health content as a 'hook'.

The reflexive dynamic envisages a 'bottom-up' community-led and collaborative healthcare structure. It foresees a shift from an emphasis on medical and pastoral care to one of 'health care' and 'telehealth', and a movement from episodic, acute care to preventative and long-term care, focusing on outpatient and self-managed delivery rather than inpatient care. Collaborative knowledge technologies open up spaces for marginal practices, and the development of 'techniques of self-mastery'. It anticipates the erosion of traditional authority structures centred on the clinician and the emergence of collaborative citizen, community and patient-managed institutional and administrative structures. This interpretation reflects a common theme of devolving power and control to both the individual and 'the community', implying a shift in resources from secondary and specialist care centres to primary care and to self-managed care. Health issues become integrated in a more holistic, community-based 'life world' system in which health is linked to other issues such as education, employment and re-generation. This notion of 'holistic self-care' is underpinned by the adoption of technologies that reflect collaborative practices, for example a shift to LINEX and 'open source' platforms.

Against this background, the policy framework which shapes the policy recommendations and design principles proposed below is grounded in an 'evolutionary' model, based on the management of these three contesting dynamics. On the one hand, it is clear that market-driven policies to some extent undermine the vision of citizen empowerment. On the other hand, policy needs to provide real muscle to give substance to what is currently the rhetoric rather than the reality of citizen empowerment. It would be naïve to expect policy-makers to embrace the lexicon of post-modern critical theory, and open up spaces within the health domain to support the ascendancy of 'lifeworld' over 'system' (to over simplify Habermas). But there is a good argument to support the proposition that encouraging marginal practices and the application of techniques of 'secondary instrumentalisation' in the health technology design and production process will realise mutual benefits for the established 'cultural hegemony' and those disenfranchised by it. Why? Because building in flexibility within the process of 'technical coding' allows for more creativity, and the development of culturally-relevant and effective technological artefacts. Bottom line, it creates more market-consistent products and services.

4.4 Policy Recommendations

Applying this 'evolutionary' framework to promote the effective development and use of digital collaborative health information and support systems suggests a number of key policy agendas and recommendations:

Managing conflicting dynamics

As discussed above, the political and socio-cultural environment surrounding health technologies is volatile, contested and still evolving. In principle, there are potential benefits in terms of both direct health outcomes and indirectly through the integration of health issues with other elements around 'e-democracy', that could be realised via digital collaborative health information and support systems. In practice, the evolution of these systems is in its infancy, and there is some evidence identified by the study that digital health content is to some extent being deployed as a device to sell consumer services, for example cosmetics, sex aids and dietary products. Generally speaking, business doesn't really see the promotion of innovative knowledge creation partnerships involving professionals and 'laypeople' as commercially interesting – except where there is a direct return or prospect for telecommunications infrastructure. The commercialisation of digital health information and support systems is currently being driven through the 'digital value chain'. One important feature of this is the use of on-line health information services as a bridging point for the packaging of other services, such as 'lifestyle' consumer goods; travel; sexual health and diet. Another is the linkage with pharmaceutical products – particularly 'off-shore' pharmacies. Emergent business models are beginning to focus on 'hybrid' systems, for example using cell-phone technologies, and networking especially wireless networking and voice and speech technologies such as IVR (interactive voice response) are among the key future developments for healthcare.

Recommendation:

Policy makers need to be aware of the need to encourage market innovation in the field of health technologies and the diffusion of products and services of common interest. Policy needs to address a number of market 'pressure points' that have the potential to subordinate common and public interests to those of the market. These include: the use of health content as a 'hook' to reel in consumers; the infiltration of web sites by commercial organisations masquerading as community support agencies; the capability of commercial alliances to dominate agenda-setting through the deployment of digital health information services.

Infrastructure and Delivery platforms

From a number of perspectives – through the development of the 'discursive' typology, through the review of state of the art and audit of systems and services – the project results point to a relative 'conservatism' in technology development and service design. The evidence suggests that there is a low

level of utilisation of established technology platforms used to deliver digital health information and support services. According to one of the studies reviewed in the RECKS project, for health web sites, the average individual page view time is 30 seconds; an average session lasts 5 minutes; 90% of users only visit a site once. For health kiosks, the average 'visit' is 1.5 minutes; an individual page view time 11 seconds, and only 14% of the potential audience is reached.⁴ Similarly, our assessment of the use of DiTV as a health support medium highlighted technical constraints associated with the DiTV platform that considerably restrict its interactivity (for example, low screen resolution and limited navigational capabilities; limitations on type of content) that lead some experts to predict its use as a 'mass audience' platform will not happen for some time. On the other hand, we identified experiments with both novel (cell phone and hand-held technology) and enhanced traditional media (digital radio) that were being used to deliver digital public services, with a particular focus on 'hard to reach groups' like young people.

Recommendation:

Initiatives are required to promote more innovative deployment of 'hybrid' 'integrated' and 'convergence' platforms, and the use of 'alternative' platforms and infrastructure. Examples include cellular phone technology and Digital Radio .

Promoting social relevance and cultural meaning

The inherent 'technological conservatism' described above reflects a broader set of issues around the separation between health technologies and 'lifeworld'. To work effectively, digital health information and support services need to be embedded within the social milieu of the users whose needs they serve. This needs to be done in a holistic way – not simply siteing kiosks in supermarkets and primary care trusts. For example, the Community Digital Network developed by the regional government in Extremadura, Spain, has developed a regional digital network based on linking together localised centres of cultural and symbolic relevance, like schools and community centres. Health content is part of an integrated package of community-based services that encompass environmental initiatives, skills development and cultural services. Digital health information and support services are co-developed through partnerships between citizens and local administrators.

⁴ Digital consumer health information and advisory services in the UK: a user evaluation and sourcebook, D Nicholas, P Huntington and P Williams, CIBER, City University, London, 2004

Recommendation:

Digital health information and support services need to be part of an integrated 'community empowerment package' – for instance linked to re-generation and re-development strategies. This could be done for example through developing partnerships with existing initiatives like 'Healthy Living Centres'. It implies the more widespread use of 'alternative' digital platforms and infrastructure, such as LINEX. To promote integration, and the social dimension of health technologies, tender procedures should demand more explicit 'social contextualisation' requirements from potential service suppliers.

Knowledge production and knowledge management

A major problem identified by the study concerns the status of 'tacit' knowledge and anecdotal data. The results of the study suggest that professionals still mistrust 'lay expertise' and experiential knowledge. As an example, content development and content review in the 'MEDCOM' system is entirely controlled by health professionals and administrators. This reflects the dominant 'learning paradigm' employed in digital health information and support systems generally, as underlined by the audit of systems and services. The results highlight a gap between 'anecdotal' evidence and evidence produced by 'gold standard' methods. A possible solution to this problem could be to develop new forms of knowledge typologies that bridge this gap – for example through meta-analysis and systematic review of anecdotal data to produce 'illustrative' medical protocols.

Recommendation:

Research is needed to produce more effective methodologies to evaluate 'evidence bases' that are not derived from clinical trials. This implies the development of an initiative for systematic review of non-clinical health knowledge, to produce an equivalent to Cochrane systematic reviews. A practical outcome of this initiative could be the development of a national database of resources of 'lay' expertise.

There is some evidence from the case studies to suggest that 'empowerment' of patients and citizens happens in restricted ways, as a result of the 'colonisation' of key knowledge creation, management and dissemination functions of collaborative knowledge systems by professionals and intermediaries. This reflects the interplay of complex structural dynamics (around the hegemonic nature of professional expertise) and socio-cultural dynamics (around things like the literacy, language and cultural practices of excluded groups). Against this background, the case studies also provided some evidence that, whereas the policy environment favours supporting initiatives to promote more effective knowledge networking between health practitioners, it is less amenable to funding initiatives that focus on the

'cognitive divide' – for example exploring the use of innovative and alternative forms of media to text.

Recommendation:

Funding should be directed towards exploring novel forms of media (particularly 'non-text' based) that can address some of the factors that maintain the 'digital divide', but with a particular focus on 'cognitive' variables.

4.5 Design Principles

4.5.1 Overview

The starting point for developing the design principles set out below derives from a key conclusion of the study:

The effectiveness of collaborative knowledge systems in providing health information and support services is dependent more on social, cultural, institutional and economic factors than on the 'technical' properties of the platforms and tools themselves, or on detailed design features, such as graphical user interfaces.

This conclusion is supported by the data produced by the intensive case studies carried out in the project. These data suggested that the main barriers to participation in collaborative knowledge systems (both as a 'user' and as a 'collaborator') were:

- Cultural constraints – the low representation of 'excluded groups', such as black and ethnic minority groups; young people, sometimes gives the impression for certain types of potential user and collaborator that these systems and services are 'owned' by someone else
- Interest group isolation – systems and services are typically 'colonised' by particular interest groups (professionals; specific illness interests). This generates a 'cycle of exclusivity and exclusion' and the perception of an absence of 'sharing culture' for public and community groups
- Technical complexity – the technical features of the tools and services are perceived as unfriendly and difficult to use
- Resource pressure – there are real costs involved in collaboration. These costs are more 'direct' within the context of health professional day to day life, but there are costs associated with collaborating for citizens and patients
- Organisational issues – these issues vary considerably, and include: difficulties in accessing the services; inadequate technical support; lack of human 'mediation' or 'moderation' of services.

The striking common denominator of this range of constraints is the social dimension. Only one of the five key constraints is about technical problems.

Yet, even in this case, the evidence suggests that technical issues around the effectiveness of health technologies are culturally mediated, since ‘computer literacy’ is highly correlated with factors like: social status, gender, social skills, educational status. Similarly, resource pressures are a major constraint to participation in the process of knowledge creation and networking. For professionals, like GPs, these pressures are measured in terms of lack of time. For ‘excluded groups’ , like an unemployed single parent, resource pressures are mediated through the real costs of going on-line, and through the opportunity costs of active participation instead of, for example, looking for a job.

In this context, we propose below two sets of design principles: firstly, a set of ‘priority’ principles aimed at promoting culturally-relevant and socially embedded systems and services. Secondly, a set of ‘design specific’ principles aimed at supporting (‘fine tuning’) socially embedded design.

4.5.2 Promoting cultural and social relevance

Design principle

Collaborative knowledge systems need to simulate and interface with communicative practices that reflect real ‘life-world’ experiences of participants.

As the RECKS ‘audit of systems and services’ showed (see Annex 1 to this Report), health promotion and health support messages work best when supported by ‘holding techniques’ that precipitate and retain interest. These techniques are essentially ‘hooks’ to attract users, but act as devices to promote user engagement and interaction. They include elements like games and quizzes. The evidence shows that these techniques work best when they can be applied in the users’ day to day life. For example: a health promotion campaign on nutrition and healthy eating was supported by an on-line quiz that asked participants to list their weekly shopping.

Design Principle:

System design and implementation needs to embody two key features: fitness for purpose and fitness for context.

The case studies clearly showed that there was a clear inter-relationship between service identity, motivation level, utilisation level and perceived outcomes and benefits. The key question – and dilemma – this raises is ‘fitness for purpose’. Theoretically, collaborative knowledge systems imply the adoption of a ‘mutual aid’ health support model (collective empowerment); an *exchange model* of empowerment (recognising that both service users and professionals possess equally valid expertise) and a *constructivist* learning approach (recognising that knowledge is socially constructed and different stakeholders have different perspectives of reality). However, the case

studies exhibited different configurations of these health, empowerment and learning dimensions, reflecting different types of purpose. For example MedCom, which serves a population composed entirely of professionals as end-users, performs perfectly effectively using a conventional 'top-down' and 'transmissive' approach.. HVN and DIPEX adopt a 'partnership-enablement-situational' combination. This reflects brokerage of health services and support by experts; the development of capabilities through promoting participation and involvement, with guidance of experts and professionals, and the embedding of learning methods and practices reflect the social and cultural environment of users. In other words, both HVN and DIPEX replicate to some extent existing 'expert-dominated' power and status controls and structures within the collaborative system. Whether this reflects 'fitness for purpose' (i.e. optimises the effectiveness of the services) or whether it maintains the power status quo is a question that can only be resolved through the way in which the service puts into practice its 'vision' and 'mission'. In this sense, the 'acid test' is 'fitness for context'. The case study results demonstrate that digital health information and support systems work best when they engage with 'practices of the lifeworld' for example through the use of true stories and video clips. The compartmentalisation of these 'communicative tools' (examples of what Foucault would term 'practices of the self') into a bounded sub-category of the system, rather than integrating the tools and practices holistically across the system, had the effect of contributing to the fragmentation of the 'collaborative' and to the sense that control was ultimately exerted by dominant expert groups.

Design principle

Effective collaboration is contingent on getting collaborators to 'step into each others shoes' and exchange life experiences and life histories ('life swapping'), rather than simple dissemination of information. Content systems therefore need to include media that can most effectively communicate these experiences and 'narratives' – for example through video, games and simulations – rather than rely on conventional texts like articles.

The RECKS study showed that the most effective forms of collaborative knowledge production occur when new knowledge emerges as a result of synthesis between different (and frequently opposing) constructions of reality. These constructions occupy different mediations: they can be mediated through different life experiences (and different life worlds); different professional constituencies; different 'communities of practice', and different ontological and theoretical positions. This means that collaborators need to exchange life histories ('life swapping') rather than simple information. A basic example in digital health systems highlighted by the study is the use of 'True Stories' – video clips of what it is like to live with Alzheimer's.

Design principle

Digital health information and support systems have to be integrated within an underlying pedagogic model. This pedagogic model needs to be consistent with the configuration of user profiles, user needs, scenario of use and organisational arrangements of the system and service being delivered. Since collaborative knowledge production embodies 'lifeworld' exchanges and 'life swapping', transmissive (i.e. conventional expert-consumer) learning models are likely to be unsuitable for all but the most basic forms of information dissemination systems. Constructivist approaches are likely to be more appropriate, especially for community-based services.

The action research experiment carried out in collaboration with the 'HERO' project successfully applied the learning derived in the RECKS project from 'state of the art' reviews and from the case studies. A significant contributing factor to the successful outcome of the action research was the deployment of a 'blended e-learning' approach, based on constructivist and 'scaffolded' learning models. This was consistent with the need to create a flexible learning environment for young people whose experiences of health management, personal development and education had been negative. Conversely, the RECKS case studies showed that the most effective pedagogic approaches associated with promoting collaboration between health professionals were based on more formalised models (action learning; instructionism) intended to foster 'communities of practice'.

Design principle

The adoption of a specific pedagogic approach - particularly those derived from constructivist paradigms - implies the active involvement of 'users' both in the design of the system (across the full range of functionalities – content; interfacing; delivery; organisational arrangements) and in the co-production of content.

As an example, the 'mission statement' of the Health Voice Network (HVN) underlines a commitment to user involvement: "The Health Voice Network is all about people helping each other by sharing their experiences, ideas, knowledge, questions and skills. We ask everyone to register with us, so that members can communicate with each other about issues of mutual interest, and develop fruitful ongoing relationships. By registering, members make a commitment to give, so that they in turn can receive. Everyone has something they can share". This commitment has played a major role in the success of the service (although there remain issues around who participates, as discussed below).

Design principle:

Health technologies need to be designed to reflect: the heterogeneity of users; the multiplicity of their identities and the evolutionary nature of their needs – including ‘transformed needs’ that emerge through engagement with the technologies themselves. Design flexibility needs to be focused on two key areas: the ontological models deployed to categorise and structure content and the user interfaces that shape the ‘look and feel’ of the technologies.

A key conclusion of the project is that users make up a diverse and heterogenous universe, ranging from individuals whose identity and group membership is continually being re-constituted, through members of culturally defined "life worlds" through various specialised "communities of practice" to formally trained expert communities. Moreover, their identity, lifestyles and needs are continually changing. As the ethnomethodological school of sociology argued some time ago (Garfinkel; 1967; Festinger, 1957), group membership, identification and behaviour is subject to a continuous process of 'social shaping'. In other words, target groups are 'moving targets'.

As an example: Analysis of the RECKS case study data showed that DipEx and Health Voice Network user motivation and participation patterns vary according to demographic and socio-cultural factors (age, status and so on) but more importantly in relation to the discourses they create round 'medicalisation'. This reflects to some extent 'life cycle' models of health behaviour - for example the 'Stages of Change' Model; (Prochaska and DiClemente 1984). Stages can range from the 'worried well' through to someone who has a medical condition, to someone who has to care for someone with a medical condition, and so on. However, a key issue is that users can shift from stage to stage, occupy multiple stages, and construct very different discourses around the same health issue. Similarly, motivation to use, and expectations of the outcome, of digital health information and support can sometimes be only indirectly health related. Our data on motivation and utilisation patterns showed, for example, that demand for content around nutrition was significantly correlated with particular discourses around 'body image' and 'self image'. These are primarily culturally rather than medically determined – related for example to how 'thin-ness' is projected and valued.

The categorisation of health content needs to reflect the multi-dimensionality of identity, lifestyle and life cycle. In the HERO example, the content ontology and classification system used to provide health support for young offenders was structured to reflect the cycle of prison life: particularly the key phases of induction; doing your time and preparing for release.

4.5.3 'Fine-tuning'

Design principle:

User involvement in the design, development and evaluation of health technologies needs to be more actively supported. This support can be facilitated through the adoption of collaborative knowledge systems themselves within the design process – for example through enriched document systems; reflective Discussion Groups and knowledge creation and editing functions that allow users a role as co-developers. However, technological tools also need to be supported by improved technology development and project management procedures and practices that aim to reduce the 'expert-lay divide' in design.

The diversity of users and the multiplicity of user needs identified by the study illustrates a perennial design problem: user engagement in design. A conclusion of the study was that it is possible to develop two distinctive typologies of system – those that focus on primarily instrumental aspects of design and engineering, and those that focus on discursive aspects, reflecting the embedding of 'symbolic and social meanings' into technology.

From an instrumental perspective there is plenty of evidence from our study to suggest that, despite lip service being paid to user-involvement and usability, in practice user engagement in design is typically rhetorical. In the RTD (research and technology development) world, user involvement is to some extent embedded in the 'programme architecture' of research programmes (for example through User Panels and formative evaluation). In the world of production, these institutional practices are far less institutionalised.

From a discursive perspective, the study suggests – at least in theory – that developing spaces for 'marginal practices' in the design process can encourage more creative and innovative possibilities in the design and development of collaborative systems and services. An example from the project was the co-design of the 'blended e-health and e-learning model in the 'One Spirit' action research programme.

Design principle:

Opportunities should be created for users to participate as co-producers in the design and development of systems and services, through the promotion of a more flexible approach to 'technical coding'. In practical terms, this flexibility can be supported through the application of knowledge-sharing tools.

The study showed that technology design and engineering is inherently conservative, and will limit opportunities for investing systems and services with diverse 'social meanings'. The real challenge for 'socially responsible design' is to create a discursive design space in which marginal practices can

be accommodated. Creating such a radically different design space is not a simple mechanistic act, but entails a re-think of 'learning patrimonies' that have shaped current practices – for example the learning curriculum in educational and training establishments. In turn, as the case studies and action research results show, effective collaborative knowledge systems require the engagement of diverse knowledge constituencies in the co-production of knowledge.

Design principle

The main obstacles to effective use of collaborative knowledge systems focus on motivational and access factors. Whilst these are primarily culturally and socially determined, semantic and cognitive factors also play a part. Good design embodies images, semantic cues and content organisation strategies that address these obstacles.

These issues around user involvement in design and content co-production of course beg the question as to how to encourage and support user engagement – particularly those from society's margins - in the design process. Promoting user involvement in design brings into play similar problems and constraints to those incurred in getting people to actually use the technologies, once the design, production and distribution process has been completed. The results of the study strongly suggest that the two key constraints to effective user engagement are access and motivation. These factors are primarily culturally and socially determined, as discussed in Section 4.5.1 above. Considerable attention has been devoted to social and cultural factors in bridging the 'digital divide' – designing and developing technologies that are sensitive to, and cater for, the needs of excluded groups. Examples include the implementation of standards governing design elements like font sizes and graphics to cater for people with visual impairments through to the development of 'assistive technologies' themselves (for example virtual reality wear to support people suffering from Parkinson's disease). However, semantic and cognitive aspects affecting access have remained poorly understood. For instance, it is clear that much of the health content provided through the Internet is textual, but 'hard to reach' users typically don't use text much. Moreover, our study suggested that the 'semiotics' of health technologies also play a part in reinforcing the dynamics of exclusion.

As an example, in the case of the Health Voice Network, user feedback data suggested that particular types of user were unhappy with the way that information and content was developed and presented on the web site. Their perception was that the service had been colonised by professionals, and by particular social groups who were articulate, literate and had management skills. This situation was thought to exclude a number of community 'voices' on the network. Engagement and retention of a diverse spectrum of people who could benefit from digital collaborative health support systems therefore requires more creative and novel design strategies. As noted above, games

and quizzes that reflect everyday life can stimulate engagement. The use of videos as 'True Stories' helps to make people feel they are not alone and that they can gain benefit from sharing their experience of illness with others. Essentially, technologies need to be more attuned to the 'human touch'. This ranges from the development of appropriate graphical user interfaces, through to developing procedures for managing and moderating chat rooms (an important problem in this case is that chat rooms splinter and fragment as they grow). In particular, community-based services need to reflect the 'image and identity' of the community through the use of visual metaphors that mirror its communicative practices. The health technology domain would benefit from looking at what is done in commercial sectors – for example advertising – to engage and attract participants.

Design principle:

Tools and procedures designed to promote collaborative knowledge production should be embedded within the service in a 'holistic' way, and not compartmentalised – for example by matching certain functions of the system to the skills base of certain groups. By the same token, system design and implementation should capitalise on the tacit and experiential skills available from 'non-experts' by encouraging greater involvement of non-experts in 'cross-boundary working'.

The project results show that utilisation patterns are affected by a combination of three main factors: type and profile of the user; their role and function within the system; their level of engagement with the service. The results show that in general terms, health professionals and other experts are involved at a significantly higher level and rate than patients and public. As indicated above, this pattern is related to: prevailing power structures in the organisation of services; issues associated with the skills, language and technology literacy characteristics of public and patients, and a degree of separation between the organisational 'system' of the service and the 'lifeworld' of patients and citizens. However, this situation is mediated through the influence of other factors, including: 'health status' and 'loyalty'. People suffering from a health condition use the services at a significantly higher rate than the general public or people who are 'carers' rather than patients. Patients and public who are registered users, and who are collaborators (rather than solely consumers) show higher rates of participation and utilisation of services.

ANNEX 1: Audit of Collaborative Knowledge Systems in the health domain

1. Scope and purposes of the audit

The 'Audit' forms part of the set of activities of work package 1 of the project ('Review of State of the Art'). The focus of the audit is to 'map' examples of innovative health technologies providing health information and support services, and involving the use of collaborative knowledge tools.

1.1 Objectives

The main objectives of the audit were:

- To identify and assess the position and contribution of collaborative knowledge systems within the broader domain of innovative health technologies (in terms of size, distribution, market penetration)
- To develop an initial typology of collaborative knowledge systems
- To explore the evolution of these systems over time
- To refine the typology in terms of distinguishing system characteristics
- To identify appropriate examples for further in-depth case study analysis

1.2 Definition of 'units of analysis'

Collaborative knowledge systems are defined as:

- Technologies that provide for feedback and evaluation of the knowledge and information provided (for example enabling users to rate the quality of information provided and play a part in continuous review and updating processes)
- Technologies that enable interaction between 'producers' of health information (like health professionals) and 'consumers' (like citizens and patients) to develop new knowledge that has an impact on health
- Technologies that enable the utilisation of 'tacit' knowledge in health promotion and/or support the conversion of tacit into 'explicit' knowledge
- Technologies involving the development and use of tools to represent and present knowledge in more intelligible and meaningful ways (for example the use of evolving knowledge bases, chat rooms and on-line evaluation tools in health promotion and support systems)
- Technologies that enable different discourses and social constructions of health to be shared to enable a 'new' construction to emerge as a result of collaborative engagement in knowledge sharing and knowledge creation.

This definition therefore excludes:

- Basic 'information systems' with no interactivity (for example conventional in-hospital cable television; databases limited to searching only)
- Systems using only 'transmissive' pedagogic models (for example providing content derived from 'experts' only)
- Simulation and self-monitoring health systems, such as remote clinical indicator sensing (unless there is some mechanism for feedback and review of data)

The 'Unit of Analysis' for the purposes of the Audit was defined as the 'innovation'. This could be a single project, delivering one specific service in a single hospital; a cluster of services or projects under a single initiative, or a national programme. The audit was largely restricted to established innovations providing 'real' services to 'real' users. This excludes research and technology development (RTD) 'pilots', except, firstly for the purposes of establishing the boundaries and contexts of the domain and secondly, in cases where real services were being provided to an established user population (rather than experimental or demonstration activities). In terms of geographical spread, the audit prioritised innovations within the UK. However, for comparative purposes it adopted a global perspective (including particularly EU and US based examples).

1.3 Methodology

The Audit was comprised of four sets of activities:

1. Identification of population sources and population
2. Collection of data on individual applications and initiatives
3. Data Analysis
4. Typology development and Reporting

A multi-methodological approach to data collection was adopted, using both primary and secondary data. Primary data collection involved structured interviews with key informants (for example system developers and administrators). Secondary data collection involved content and discourse analysis of web sites; promotional material; evaluation reports and similar documentation.

The data were collected using a common template to facilitate standardisation and cross-comparison (Annex I). Each item was categorised on the basis of the following characteristics:

- geographical location
- technological platforms and delivery systems used
- content domain and type
- type of innovation (technical; health; institutional; economic)
- funding and finance arrangements
- health 'scenarios' represented (promotion; support; training ..)
- organisational structure and actors involved(partnership arrangements)

- setting (e.g. single site; inter-site; regional setting; national/international setting)
- type of user targeted by the innovation
- pedagogic model and collaborative/interactive features

The audit population frame was constructed from the following sources:

- Interviews with Experts.
- Specialist health technology market research companies (e.g. Silicon Bridge)
- European institutions (e.g. Eurostat; DG-INFSO; EHTEL)
- National government institutions (e.g. NHS; Department of Health)
- Health care companies (e.g. health insurers; pharmaceuticals)
- Telecoms, hardware and software
- Database searches (e.g. Telemedicine Information Exchange; SOSIG)
- UK and European R&D Programmes (e.g. NEAT; HTA; ESPRIT, AIM, Telematics Applications Programme; IST Programme).

2. The context for collaborative knowledge systems in health promotion and health support

A number of factors combine to make the Audit a difficult undertaking, including:

- The fluidity and lack of definition of 'health technology' as a unit of analysis
- The rapidly evolving nature of the domain
- The absence of a comprehensive database of resources and examples

Definitional issues are central to our exploration of collaborative knowledge technologies in the health domain. Technology has always been fundamental to medical practice. Indeed, it could be argued, as Section 2 of the 'Review of State of the Art' points out, that one of the defining features of the evolution of 'health' in post-classical society has been what Foucault calls the 'technicisation of the self'. In modern health services, certainly in developed economies, the use of technologies in pursuit of promoting and supporting health, across all health sectors, has become routine – from everyday ophthalmic examinations, for instance, through to organ transplantation. A key distinction in the context of the evolving 'knowledge society', therefore, needs to be made between health technologies that are fundamentally instrumental, in the sense of acting as tools to facilitate the efficiency and effectiveness of medical procedures and practices (much as, say, a saw is instrumental in the practice of carpentry) and those that involve what Habermas calls communicative practices.

In the former case, health technologies can be viewed as artifacts, or devices, and are ubiquitous across the healthcare domain. In the USA, for example, the Food and Drug Administration (FDA) has developed a classification framework for medical devices that encompasses around 1,700 generic types,

grouped into 16 medical specialities⁵ and ranging from thermometers to MRI scanners. The FDA classification system embodies an implicit ontological model that is predicated on three dimensions: the intended use of the device; the indications for use, and the risk factors associated with use. To take a scalpel as an example, the generic intended use is to cut tissue; a sub-set of indications for use might focus on 'making incisions in corneal tissue', and the risk factor will generally be low (unless of course you are using a scalpel to remove unwanted nasal hair in the bathroom).

The ontological and epistemological status of technologies in the context of their role as a form of mediation between actors engaged in social interaction is central to understanding the nature of collaborative knowledge systems and their position in social and personal relations. We return to these key issues later, in our re-formulation of a typology of collaborative knowledge systems based on the results of the audit. Our starting point for this typology is to define the basis of a point of separation between medical devices as 'instrumental artifacts' and health technologies that entail active communicative engagement with the technology. This by no means an easy or clear cut distinction to make. The evolution of medical technologies means that classification systems have to accommodate things like pharmaceutical products – for example new forms of anti-retroviral drugs – but also new approaches or new applications of existing drugs – for example applying drugs conventionally used to treat bowel infections in experiments with autism. As an illustration, the current NHS/DoH Health Technology Assessment Programme incorporates around 500 assessments of 'health technologies' primarily in the form of 'reviews'. These reviews encompass a wide range of applications areas. The majority do not focus on specific technological artifacts i.e. medical devices, but rather are typically reviews of techniques and practices, for example a comparative review of different approaches to reducing the incidence of infection in hospital operating theatres. Moreover, the development of emergent new medical technologies, for example cloning and genetic modification techniques, is beginning to blur the boundaries between 'devices' (inanimate artifacts) and communicative practices.

Against this background, the benchmark used to set the boundaries for the RECKS audit of collaborative knowledge systems in health is the World Health Organisation's definition of 'health telematics':

"Health telematics is a composite term for health-related activities, services and systems carried out over a distance by means of information and communication technologies for the purposes of global health promotion, disease control and healthcare, as well as education, management and research for health."⁶

The WHO definition sets a number of parameters for our emergent typology of health-related collaborative knowledge systems. These include:

⁵ FDA, 2002

⁶ 'Health Policy for all in the twenty-first century: health telematics', WHO, January 1998

- A focus on data and information processing infrastructure, and on knowledge production
- A focus on 'networking' between different actors
- A broad functional and sectoral representation of health-related activities

On the basis of the WHO definition, a number of initiatives began to develop to impose a classification framework on this emerging 'health informatics' market. A typical example is CEN/TC 251, the European Commission initiative for establishing standards in health care informatics and telematics, which established standardisation working groups in seven main areas:

- Health Care Information Modelling and Medical Records
- Health Care Terminology, Semantics and Knowledge Bases
- Health Care Communications and Messages
- Medical Imaging and Multimedia
- Medical Devices (communication with)
- Health Care Security and Privacy, Quality and Safety
- Intermittently Connected Devices (including patient-data-cards)

This provides an illustration of early categorisations of health informatics. A much more developed framework, which provides the context for this current Audit is the study commissioned by the European Commission in 1998 on the impact of telematics on European healthcare.⁷ This study carried out an extensive analysis of state of the art in the development, production and diffusion of health technologies throughout the EU, and identified a total of 277 examples of innovations in use. The study produced a typology of health telematics systems and services, which reflects nine 'clusterings' of socio-technical systems centred around a common 'innovation image'. They comprise configurations of particular technological platforms, institutional arrangements and interactions and collaboration between user groups - suppliers and purchasers of health care; providers of telematics services; local, regional and national authorities; clinicians and healthcare managers:

- **Information storage and retrieval systems.** such as Electronic Patient Records (EPR) to facilitate the integration of patient data held by different service providers; 'smart cards' to hold individual patient data on medical history; insurance and social security data.
- **Resource management systems.** These facilitate the co-ordination and management of information flows and actions in the management of health care sites. Such systems are typically referred to generically as Hospital Management Systems (HIS).
- **Decision/clinical support and collaborative working systems for healthcare professionals.** Applications areas include knowledge based systems to assist in the application of medical procedures and

⁷ Cullen, J et al 'TELMED: impact of telematics on European healthcare', CEC, 1998

protocols; multimedia telematics networks for diagnosis and treatment of medical conditions like epilepsy, and systems to promote the dissemination of research findings and new techniques in fields such as oncology.

- **Infrastructure, Regional networks and service integration systems.** These typically focus on the development of common telematic systems and services, utilising open systems architecture in order to promote both technical and organisational integration. A common feature of such scenarios is the adoption of EDI (electronic data interchange) messaging and multimedia services.
- **Telecare/diagnosis scenarios** embody notions of delivering healthcare through real-time remote diagnostics; surgical, medical and therapeutic consultancy. They address particularly the problems of delivering healthcare to remote and transient client groups., and include two main sub-clusters: Teleradiology - the use of telecommunications and informatics to transmit and receive x-ray images for the purposes of diagnosis, and Telepathology: the use of telecommunications and informatics across a range of pathology services, for example the results of laboratory analysis. They are closely linked to another cluster:
- **Teleemergency** - telematic systems to co-ordinate and operationalise emergency service interventions (for example navigation systems to assist ambulance services in locating emergencies in remote areas).
- **Community/Telehealth scenarios** follow the logic of an expanding and accessible knowledge base for citizens as a result of universal access to information highways. They include automated community health monitoring and evaluation, and health promotion and disease prevention using public access multimedia systems.
- **Medical Imaging** - the storage, retrieval and dissemination of medical images, for example ct scans, x-rays, magnetic resonance images. This set of applications is typically linked to two main sub-clusters: Teleradiology - the use of telecommunications and informatics to transmit and receive x-ray images for the purposes of diagnosis, and Telepathology: the use of telecommunications and informatics across a range of pathology services, for example the results of laboratory analysis.
- **Teletraining** - the utilisation of distance teaching and training within the medical domain.

Figure 1 shows the distribution of these clusters within the European health system in the latter part of the 1990's.

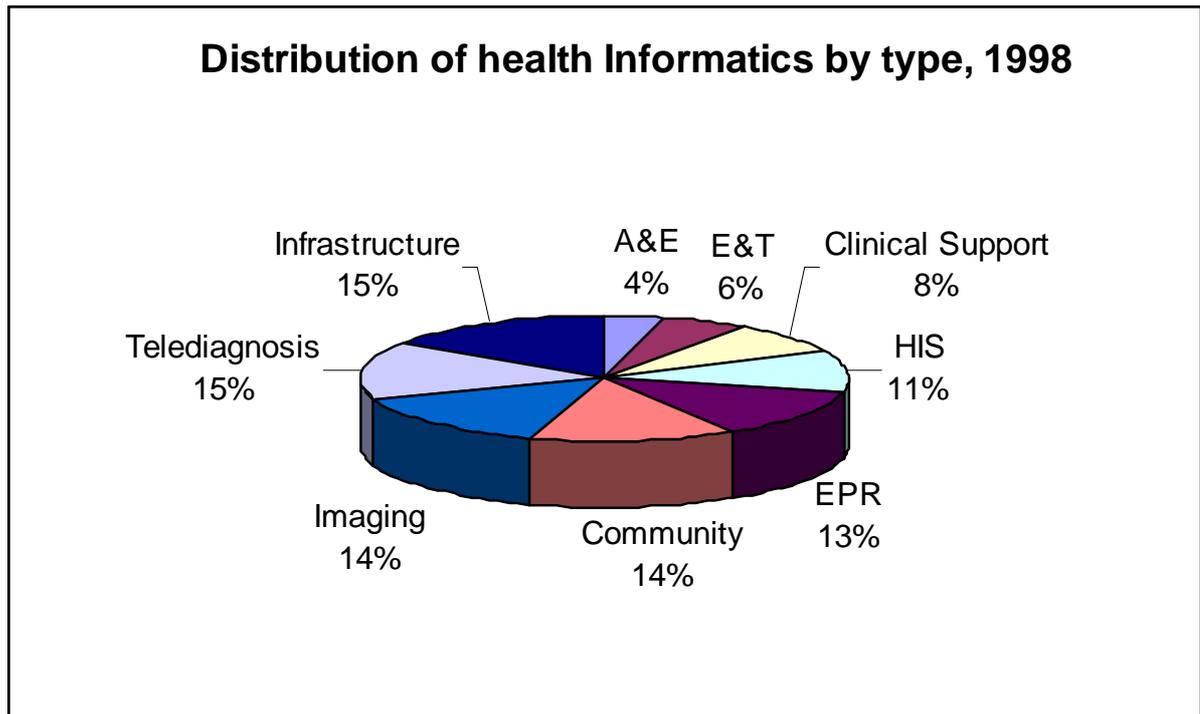


Figure 1

Figure 1 shows:

- A broad spread of applications environments is represented within Europe, with no real dominant concentration in a particular type.
- However, implementation has been most marked in the EDI, medical imaging, telediagnosis and electronic patient record sectors, each accounting for broadly 15% of the total applications identified.
- The sectors under-represented are in teletraining and telemergency services.

It should be emphasised that the broad sectoral categories discussed above do not represent mutually exclusive telematics scenarios for healthcare. Commonly, a particular application or intervention will embody a range of generic products and services, for example utilising EDI infrastructure networks and medical imaging applications to provide telediagnosis services for users.

For the purposes of the RECKS project, the research team re-assessed the original data from the TELMED study to identify the representation of collaborative knowledge systems within the population universe of health informatics. This analysis showed:

- Only 22 (7%) of the 277 examples of systems and services identified in the TELMED audit could be described as 'collaborative knowledge systems' in terms of our working definition (described in Section 1 above).

- These systems and services were primarily used in community-based telehealth scenarios and, to a lesser extent, in decision support systems aimed at promoting collaborative working between clinicians.

To develop this typology further, and to plot the evolution of health technologies since the TELMED study was carried out, the RECKS audit then analysed the data from a recent market study on health technologies, carried out in 2003 by Silicon Bridge. Silicon Bridge carries out regular surveys of the health technology market in terms of specific systems and services available for commercial use in the UK. Figure 2 compares the spread and distribution of health technology systems in 2003, as reflected by the Silicon Bridge survey, compared with the 1998 TELMED study.

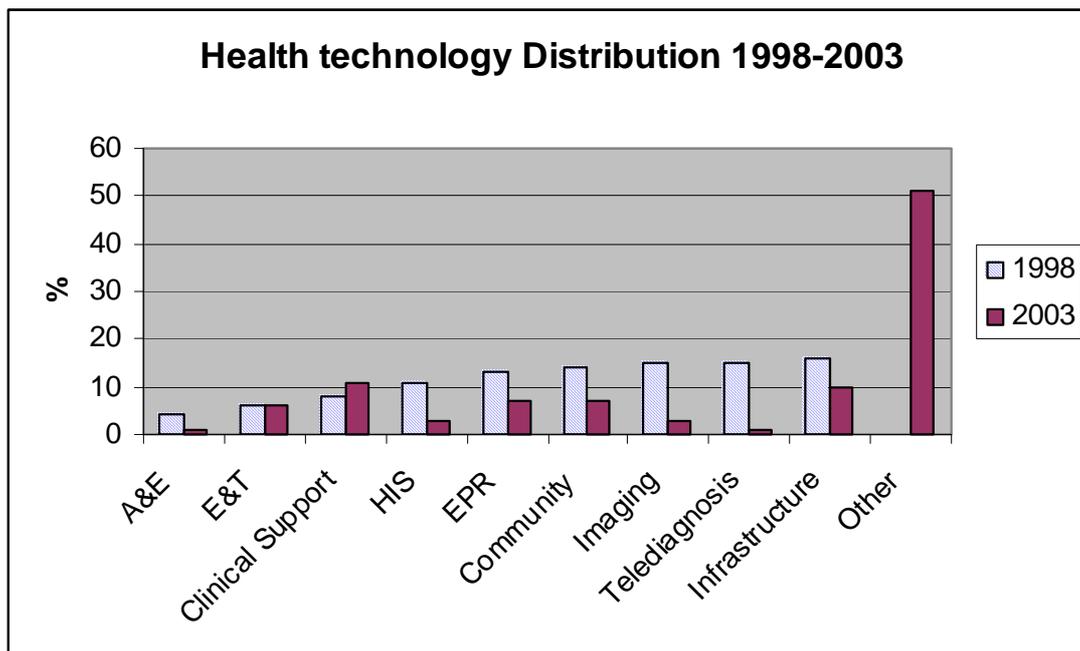


Figure 2

Figure 2 shows:

- The market has expanded considerably between 1998 and 2003. The Silicon Bridge market survey – which represents systems available to UK consumers – lists 431 different systems available. This compares with the 277 examples identified by the TELMED study for Europe as a whole.
- There has been a significant broadening of the range of technologies developed. Over half the systems documented in the Silicon Bridge market report are applications in new sectors, and with new functions.
- This reflects a number of trends: a maturing market which has been moving from basic infrastructure and stand alone systems to integrated services; the development of more complex technology ‘value chains’; the harnessing of technologies to improve the efficiency of service delivery (i.e. the increased bureaucratisation of health technologies).

For example, Infrastructure accounted for 15% of the total health technologies in 1998 and less than 10% in 2003. Similarly, imaging applications and telediagnosis systems each accounted for 15% of the total identified in the 1998 TELMED study but less than 2% of the market identified by the Silicon Bridge report in 2003.

- The new systems and services currently on the market include the following:
 - Primary care (5%)
 - Care planning (4%)
 - Departmental support (10%)
 - Clinical management (5%)
 - Records management (4%)
 - Patient relations (1%)
 - Commissioning (2%)
 - Accounting (13%)
 - Hotel services (5%)
 - Public health (1%)

To provide additional triangulation in terms of setting the context for health technologies, the Audit also analysed trends in research and technology development (RTD) in the health domain on the basis of data on RTD projects funded under successive European Commission 'Framework' programmes. These represent the largest investment in technology development in Europe, running into scores of billion euro in each Framework. Programmes analysed include AIM (Advanced Informatics for Medicine); the Telematics Applications for Health Programme (TAP); the Information Society Technologies Programme under Framework V and the current Information Society Technologies Programme in Framework VI.

Table 1 shows the evolution of health technology since the early 1990's to the present, as reflected in these Framework Programmes.

Table 1: Evolution of health technologies in EC Framework Programmes, 1990-2006

% projects	FP3/4	FP5	FP6
Period	90-98	98-02	02-06
Clinical Support	10	12	22
Electronic Patient Records	6	1	0
Hospital Information Systems	8	2	0
Infrastructure	6	3	0
Imaging	4	9	6
Community/Public health	11	5	0
Emergency	6	0	0
Training	2	1	0
Telemedicine	10	9	11
Networking/Databases	13	11	0
Remote monitoring	2	22	0
Standards	5	4	6
Programme support	15	10	0
Logistics	0	3	0
Modelling	0	5	0
Robotics	0	2	6
Data mining	0	0	17
Biosensors	0	0	28
Integrated systems	0	0	6
Total project base(number)	125	159	18

Table 1 shows:

- Under Framework 3 and 4, from 1990 to 1998, the development of health technology research mirrors that of the health services market itself, as described in the TELMED study, with a concentration of RTD effort in telemedicine/telediagnosis, community health applications, imaging, clinical support systems and management and administration systems, including electronic patient records, hospital information systems and distributed databases.
- In recent years, from 1998 to 2002, research in health technologies has moved towards a vision of 'e-health' scenarios, with a particular focus on remote monitoring and surveillance systems. These embody notions of personal self-management of health and are consistent with a prevailing policy climate predicated on promoting a movement away from investing resources in acute care and devolving more responsibility for health to primary care providers, and ultimately to citizens themselves. They typically entail remote downloading of clinical marker data by patients suffering, for example, from diabetes, to enable shared monitoring and management of conditions between a range of care-givers, including patients themselves.
- At the same time, RTD between 1998 and 2002 is also characterised by the emergence of leading edge technologies – for example in

robotics - in tandem with the consolidation of stable technologies like EPRs.

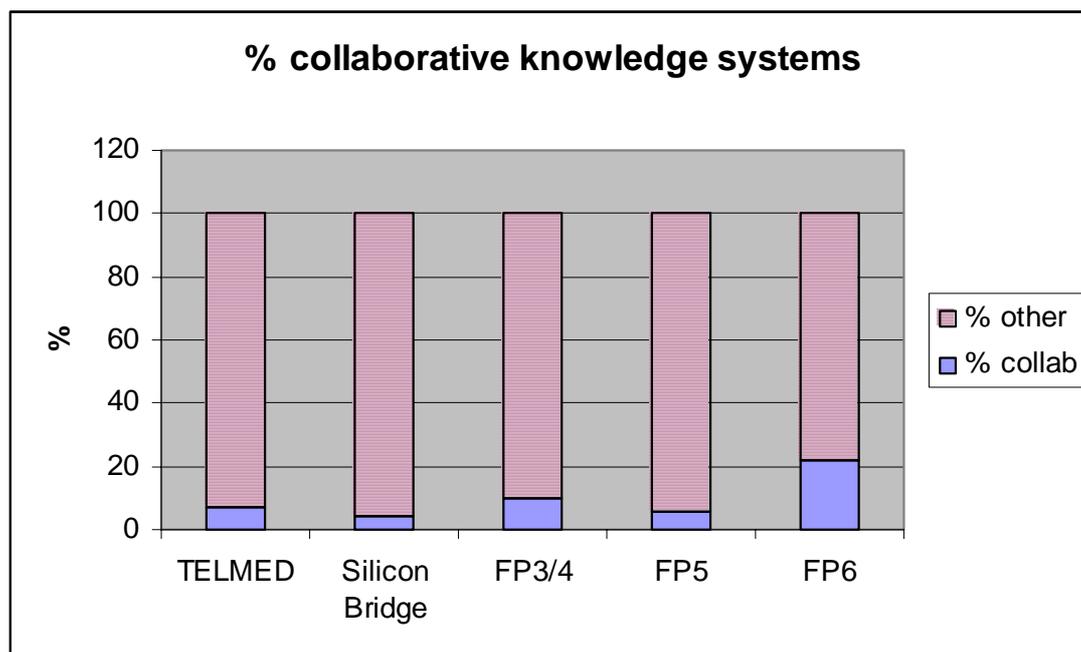
- In the current Framework 6 Programme, this investment in 'high end' technology has increased. The current Framework Programme has radically changed the funding instruments available for RTD, moving from autonomous self-contained projects with an average cost of euro 2 million, as in previous programmes, to large-scale 'Integrated projects' and 'Networks of Excellence' – which explains the reduction in numbers of health technology RTD projects from 150 in FP5 to only 18 in FP6. What is striking about current health technology RTD is the high concentration of investment in two key areas: data mining and biosensing devices.

The effort in data mining systems reflects a growing consolidation of interest in the integration of different systems and services in pursuit of 'seamless' health delivery services that can be customised and tailored to specific organisational – and individual – user needs, and also to address 'just in time' demands. Examples include AMICA – assembling data and knowledge at the point of care to improve medical decision making and prevent errors; COCOON – building knowledge driven and dynamically adaptive networked communities. The effort in biosensing systems is resonant of 'frontier medicine', embracing the vision of convergence between humans and machines. Examples include: INTREPID – a virtual reality wearable multisensor system for phobias.

A key conclusion of this context-setting analysis is that the health technology domain itself is relatively small. More importantly, as indicated above, the relative contribution of collaborative knowledge systems to the development of health informatics, health technologies and, latterly, e-health has been small. Figure 3 shows their market share (as reflected in the TELMED and Silicon Bridge reports) and their representation in RTD output.

As Figure 3 shows, the percentage of collaborative knowledge systems available on the market, and under development in RTD programmes, has consistently run at less than 5% of the total output over the past decade. In the current FP6 programme, the percentage of collaborative knowledge systems has risen to 20% - but this reflects the small baseline of current health projects.

Figure 3: Relative representation of collaborative knowledge systems in the e-health market and e-health RTD



However, set against this relatively small and highly bounded investment in health technologies by commercial companies and the research establishment has been the proliferation of health-related information on the web. As an illustration, a Google search for health-related information provides the following returns for a range of indicative categories (Table 2).

Table 2: Numbers of web pages on indicative health-related searches

Category	Pages (million)
Health advice	8.9
Look after your health	9.2
Online Doctor	6.2
Weight loss	8.8
Diet advice	3.6
Sexual health	6.2
Mental health	7.6
Coronary advice	0.2
Diabetes support	3.1
Alshaimers advice	0.2
Cancer support	5.2
AIDS advice	3.3
Lupus support	0.3

On the surface, the data shown in Table 2 would appear to support the position of a number of post-modern writers on the role played by new communication technologies in reversing the domination of the 'expert'. Instantaneous global communication, as Giddens (1994) puts it, "tends to produce cultural diasporas", where globalising influences tend to 'evacuate

out' local contexts of action. As a result, personal identity becomes highly reflexive, and everyday 'experiments with the self' become an intrinsic part of daily activities, utilising information coming from a variety of sources. Giddens therefore argues that the proliferation of social movements and self-help groups in recent years is directly related to the growth of the information society, and reflects both this heightened self-reflexivity and the effects of instantaneous global communication. Such movements, it is argued, have played a major role in retrieving power from 'experts' and in the lay retrieval of expertise.

However, the picture is not as simple as this. On the one hand, there is no doubt that health topics are top of the list in terms of web browsing behaviours. A recent Harris Interactive report calculated that 111 million adults have looked for health information on the Internet, as of February 2004, compared to 109 million in 2003 and 110 million in 2002. The annual survey of more than 1,000 American adults found that 74 percent of all those online have looked on the Internet for health information, with fewer indicating they look "sometimes" than indicated in surveys from the past two years.

However, while roughly three-quarters of the Internet population have used the Web for health information in 2003, the evidence suggests that much of the web-based resources available on health matters is in the form of standard text – for example reports on research results, and the level of interactivity is insignificant. [Jupiter Research](#) found that only 3 percent of adult Internet users held online clinical consultations with their doctors in 2003, even though 65 percent of adult Internet users said they were interested in using this service in 2002.

As Monique Levy, health analyst, Jupiter Research, observes, "Most are using the Web as a tool to gather information, but not necessarily to manage health or benefits. Only 7 percent used an interactive tool to manage a chronic health complaint in 2003."

This picture is supported by the results of the literature searches carried out in parallel with the audit. As Table 3 shows, there is virtually no existing body of knowledge or evidence base on collaborative knowledge systems in health.

Table 3: Results of database searches on collaborative knowledge systems in health

Search terms	Setoc	IBSS	BEI
Health technology	22,985	536	18
Health information systems	2500	117	8
Knowledge management systems	2320	98	11
Collaborative knowledge systems	92	5	2
Information management systems+health	587	25	5
Knowledge management systems+health	30	6	0
Collaborative knowledge systems+health	3	0	0

3. Results of the Audit

As reported above, the initial, context-setting phase of the audit process identified two counter-prevailing trends: on the one hand, the appearance of public engagement in health issues and practices, associated with the proliferation of information sources on the web, but on the other, only a very limited number of actual collaborative knowledge systems and services in use or under development. This finding was reinforced by the second phase of the audit, in which data were collected on specific examples of innovations.

Using the sources described above in Section 1, the audit produced a preliminary population frame of just over 140 examples of innovative health technologies involving collaborative knowledge systems. However, analysis of the characteristics and features of these examples resulted in a significant proportion being discarded, since closer inspection revealed that they did not meet with the requirements of our definition of 'collaborative systems'. The analysis was therefore carried out on a population frame of 47 examples.

The properties of these examples are described below in relation to a range of key defining indicators:

- The delivery platform (the infrastructure used to deliver health systems and services)
- The services provided
- The key 'knowledge domain' covered
- The revenue model adopted
- The 'knowledge production' model adopted (as reflected in the nature of interactivity between stakeholders)
- The users of the services provided
- The 'scenarios of use' implemented
- The 'techniques' used to promote interaction between actors

Figure 4 shows the distribution of the audit examples in terms of the delivery platform used.

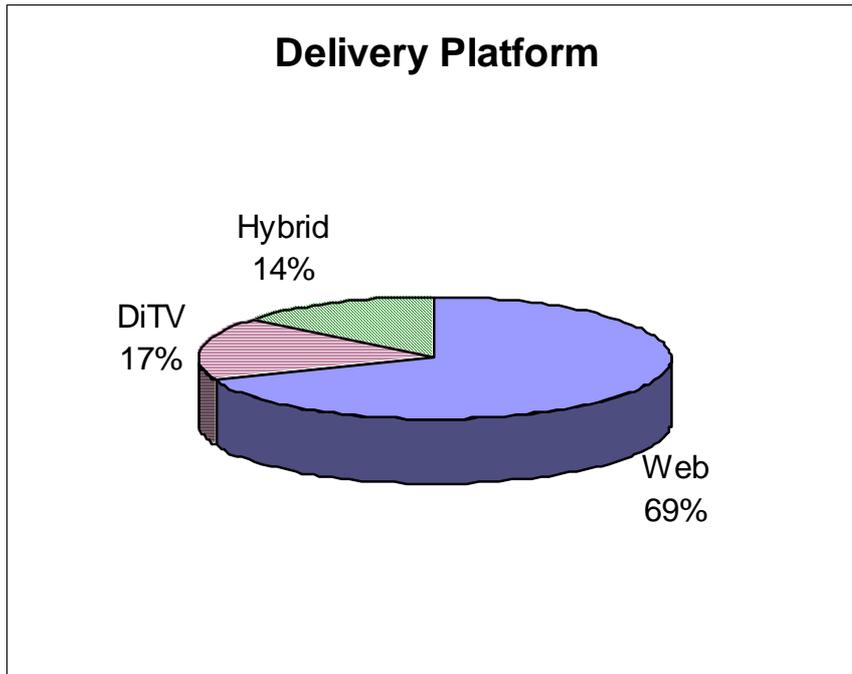


Figure 4

As Figure 4 shows, the majority of collaborative health systems and services are web-based services. Just under 20% are services delivered through digital television, and a similar proportion are hybrid systems – typically involving ‘convergence technologies’ (linking wireless technologies with web-based services for example).

Figure 5 shows the range of services provided.

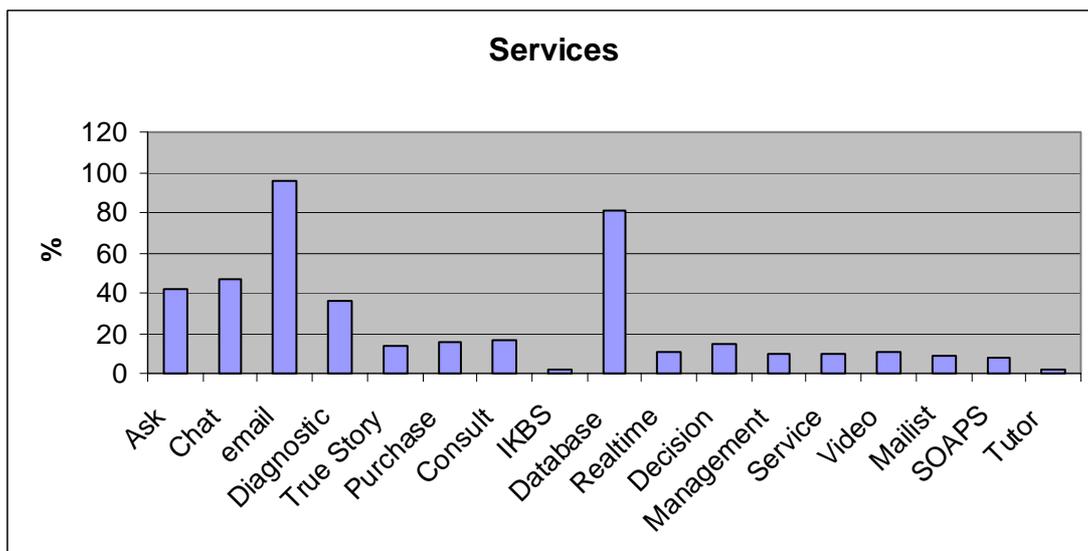


Figure 5

Figure 5 shows:

- Digital information and support services cover a wide range of services. 'Services' in this context are defined as the functionalities through which user needs are satisfied. The Figure shows the % of the audit examples for which a particular service is provided. They include:
 - 'Ask an expert' – on-line advice on a medical or health issue, typically provided by a health professional.
 - Chat rooms and Discussion Fora in which users can discuss health issues with peers and experts
 - E-mail supporting communication between stakeholders
 - Diagnostics – for example 'depression checks'; 'do-it-yourself breast examinations'
 - 'True Stories' – narratives of real-life 'medical stories', for example relating experiences of coping with Alshheimers
 - Purchasing services – for example on-line pharmacies
 - Teleconsultation – advice provided by health professionals in relation to a particular medical condition, customised for particular individuals
 - Databases – a searchable library of resources, usually classified in a category structure, and supported by a content management system; user profiling and 'advisor agent' tools and searching
 - Intelligent knowledge based systems – expert system protocols for health conditions
 - Real-time services – for example synchronous consultations with health professionals through webcam
 - Decision support services – these differ from 'ask an expert', diagnostic and teleconsultation services (which typically provide 'generic' information). Decision support services tend to address more complex, multi-dimensional issues rather than a straightforward 'single issue' problem. They are broadly split into two types: health professional support and support for patients.
 - Clinical management services – for example providing infrastructure for information and knowledge distribution between different groups of health professionals
 - Service management – for example integrating consultation with patient appointment booking services
 - Video streaming – for example providing video library facilities linked to 'true stories'
 - Mailing lists and list servers
 - SOAPS – 'seals of approval' enabling users to rate information and services on a range of criteria, for example the credibility of information
 - Interactive tutorials – for example supporting diagnostic services or training services
- The systems available very rarely focus on one particular type of service. Most collaborative knowledge systems are configured to

provide a combination of features. The typical combination would include: database; e-mail; ask an expert; chat room.

- Virtually all the systems available include some form of information database and email service. Other types of services that are relatively well-provided include 'ask an expert', chat rooms and diagnostic health checks (around 40% of the examples included one or more of these services).
- Purchasing services; expert systems; real-time services; decision support services; clinical management services; service management; video streaming; SOAPS and interactive tutorials account for a small proportion of the services provided.

Figure 6 shows the main health content areas covered by the systems.

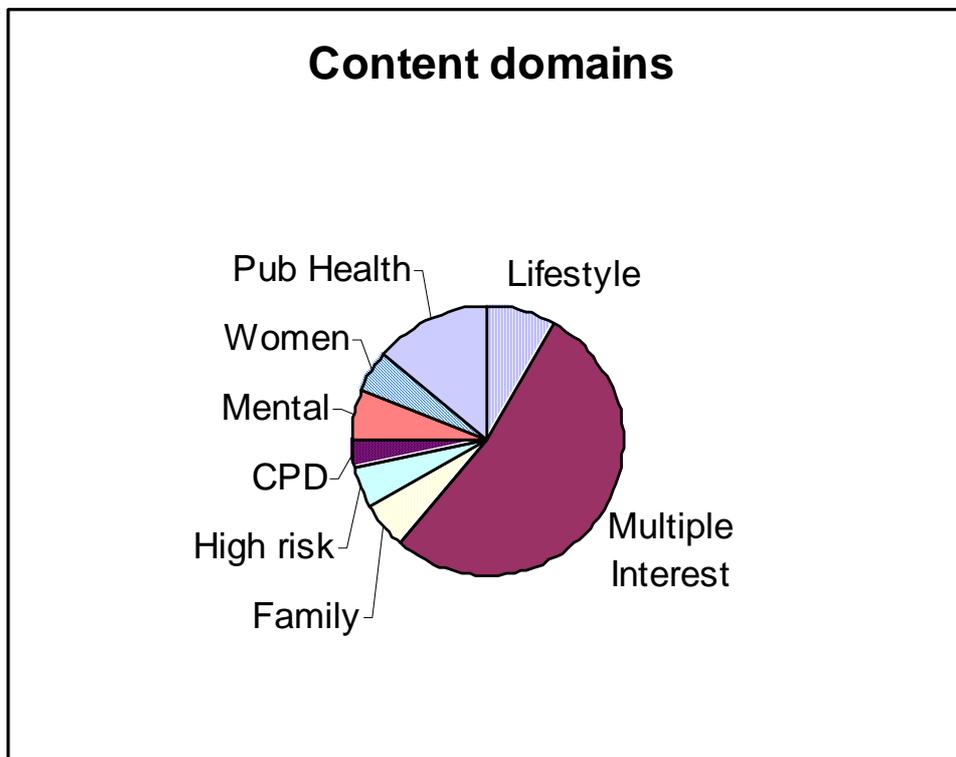


Figure 6

Figure 6 shows:

- The audit identified eight broad content domains in which collaborative knowledge systems operate:
 - 'Multiple interest' content domains. This consists of a range of specific health problems or medical conditions, usually targeted around a particular theme
 - Lifestyle – focusing mainly on diet (particularly 'weight problems'), sports

- Public health
 - Women’s health (including, for example, breast cancer and HRT)
 - Mental health
 - Continuing Professional Development – for example websites providing evidence-based reviews; results of new clinical trials
 - ‘High risk’ domains – coronary disease; cancer
 - Pregnancy and family
- The biggest proportion of the systems covered in the audit – 53% - provide ‘multiple interest’ content. Around 14% focus on public health content and just under 10% focus on ‘lifestyles’.

Figure 7 shows a breakdown of the systems covered in the audit by type of funding model.

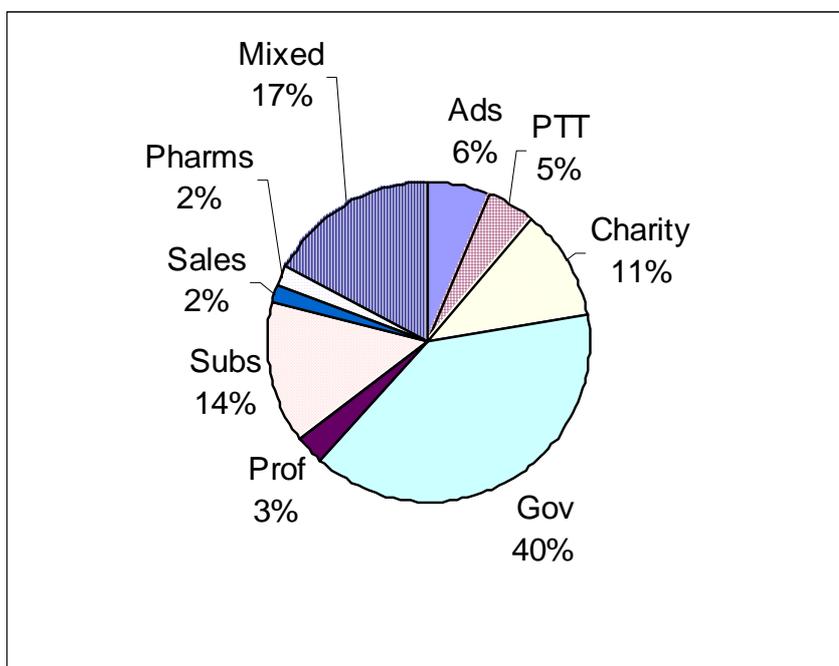


Figure 7: Funding models

As Figure 7 shows, the largest proportion of collaborative knowledge systems in health (40%) draw funding from government sources. This investment is concentrated in two main domains: public health information and ‘high risk’ domains. Another important source of funding are charities, who operate mainly in the public health and mental health domains, but also tend to fund specific medical and health interest issues. A small proportion of systems and services (3%) are supported by professional organisations, mainly to provide updating on medical state of the art.

Around a third of the systems audited represent ‘commercial’ operations. The largest proportion of these (14% of the total audit sample) are subscription services. Perhaps surprisingly, the audit suggests that advertising accounts for only a small proportion of the income generated – 6% of the total. Direct sales of products and services account for only 2% of the total, and typically

provide 'lifestyle' products (dietary supplements; weight reduction programmes) and on-line pharmacies (typically Viagra and prosac). Another form of commercial funding is services provided 'free' through telecommunications, television and internet service provider companies.

A key objective of the audit was to identify and explore the 'collaborative' dimension of emerging innovative health technologies. Figure 8 shows the types of 'knowledge production' models adopted, as reflected in the nature of interactivity between stakeholders.

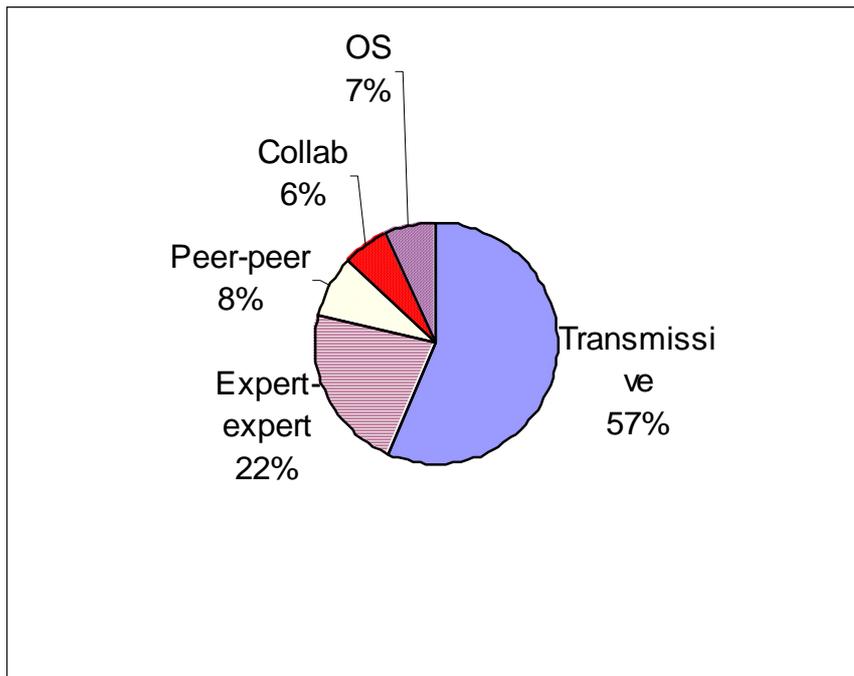


Figure 8: Knowledge production

In fact, as Figure 8 shows, the majority of collaborative knowledge systems in operation within the health domain are characterised by rudimentary modes of interactivity. Some 57% of the systems covered by the audit were classified as 'transmissive'. In these cases, the knowledge creation, knowledge-sharing and learning approaches underpinning the system adopt a traditional didactic form of interaction. Users act as passive consumers of information provided by experts and professionals. There are some functionalities built into the system to promote 'user involvement' (see section on 'Techniques' below) but these functions are primarily tokenistic. Just over a fifth of the systems covered in the audit were primarily intended to promote collaborative knowledge sharing between health professionals – expert-to-expert interactivity. A smaller number – 8% - promote active 'peer-to-peer' interaction, in the sense of enabling laypeople to develop shared understandings of and practices around health issues through, for example, on-line discussion fora. There is some evidence that these types of user-led 'constituencies of knowledge' are beginning to build evidence bases for some forms of health domains that are grounded in tacit and experiential knowledge. Another trend identified by the audit was the emergence of 'open source' systems. 'True' collaborative knowledge systems – those which meet

our definition criteria – constitute the smallest group of the innovative health technologies covered by the audit, comprising only 6% of the total. These types of innovations are associated with a movement towards developing integrated community and regional healthcare networks.

Modes of knowledge production are correlated with the type of scenarios of use in which health technologies are implemented. A scenario of use in this context is defined as the setting in which engagement and interaction takes place. Figure 9 shows the breakdown of the examples covered by the audit in terms of the range of scenarios of use identified.

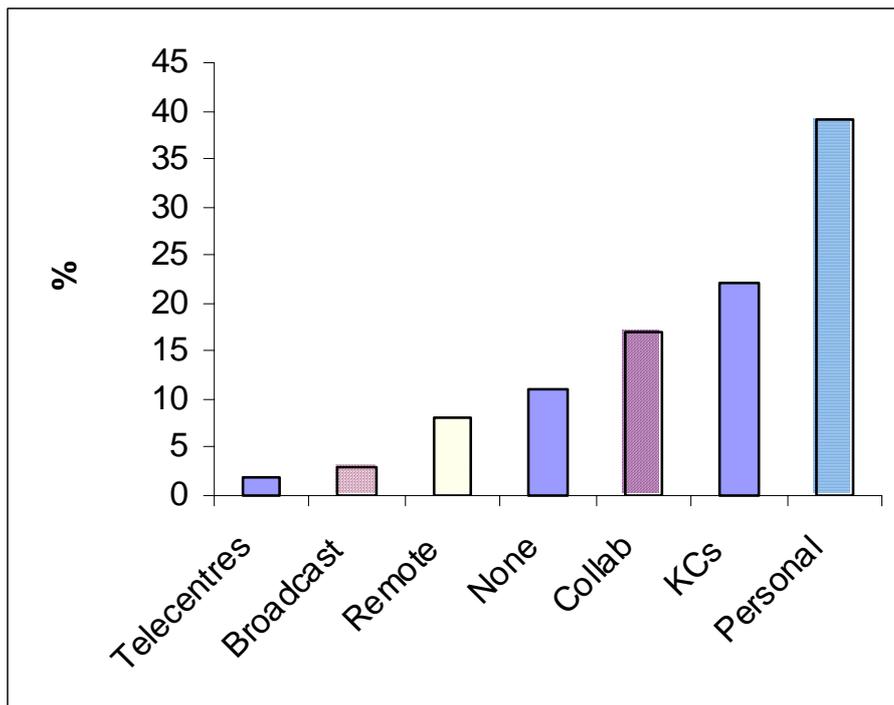


Figure 9: Scenarios of Use

As Figure 9 shows, the dominant scenario of use – around 40% of the audit examples analysed – reflects an individualised interaction between user and system. This effectively corresponds to a ‘self-managed’ health scenario, where the user has access to a knowledge base of health resources, and is normally supported in their knowledge acquisition, management and application goals through tools like search engines, user profiling systems and advisor agents. Around 20% of the health technologies covered by the audit reflect what could be described as a ‘knowledge constituencies’ scenario, based on networked communities of practice, mainly involving knowledge exchange between professionals. The ‘remote’ scenario reflects dispersed nodes of users who share common interests. The ‘broadcast’ scenario focuses on the deployment of digital interactive tv platforms using conventional ‘mass audience’ communication models. Telecentres can be thought of as virtual ‘drop in centres’ providing access points for the distribution and circulation of health information around public and community health issues.

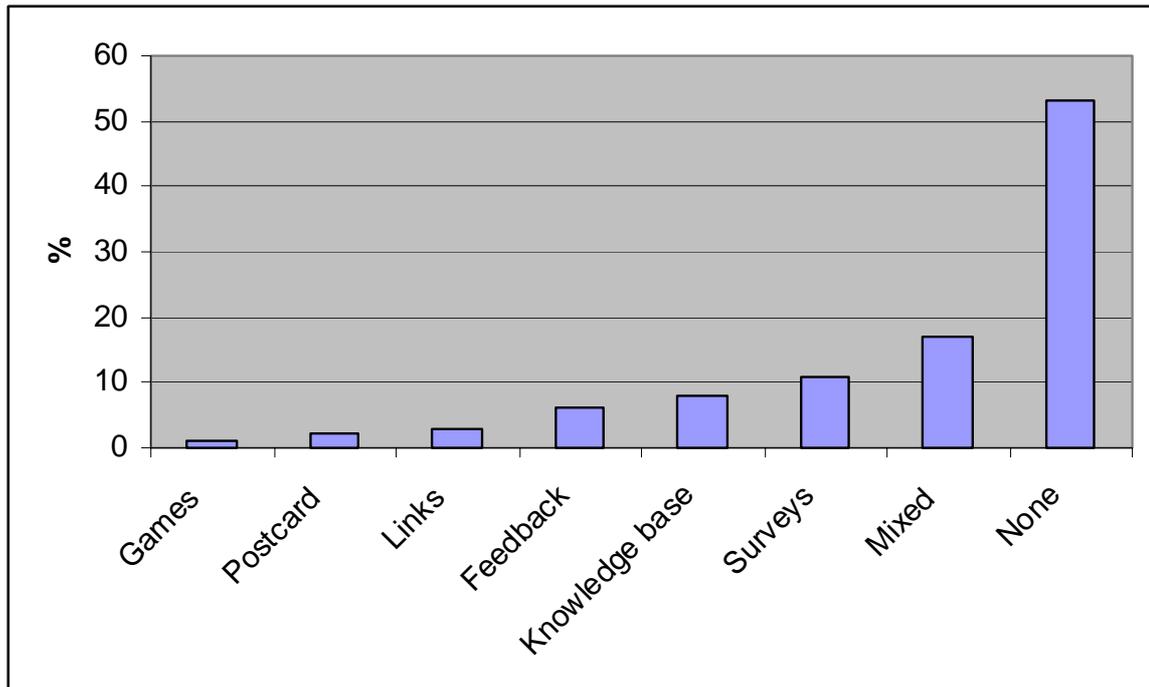


Figure 10: Holding techniques

Another feature of the health technologies identified by the audit was the use of 'holding techniques'. These techniques perform a number of functions:

- as 'hooks' to attract users
- as devices to promote user engagement and interaction.
- as data capture tools for evaluation purposes
- as a 'user interface' for diagnostic tools and services.
- as a mechanism for the capture of knowledge.
- as a means of persuading users they need a particular product or service.

Six main 'holding techniques' were identified (Figure 10):

- Games and quizzes - designed to raise interest and persuade the casual browser to become more actively engaged
- Virtual postcards – users are encouraged to send a digital postcard to a friend endorsing the merits of the system and therefore promoting more extensive use of its services
- Links – users are directed to other web sites that provide similar or more specific services
- Customer feedback forms – a simple device for promoting 'evaluation' of the system and services. They enable continuous improvement of the system and services on the basis of feedback data, and promote a sense of ownership and engagement through participation amongst users.
- On-line surveys – are essentially more sophisticated feedback forms, with similar evaluation and user-engagement purposes. Particularly in the case of sites aimed mainly at selling commercial health products,

they form part of the 'sales pitch' intended to persuade customers to buy.

- Evolving knowledge bases – knowledge develops iteratively through the acquisition of data from a number of sources: from experts (for example through the results of clinical trials); from tacit knowledge provided through the experiences of patients, for example, and through the resultant pooling and reification of knowledge through collaborative exchange. In turn, the opportunity to gain from participating in the development of the knowledge base itself becomes a 'hook' to attract, engage and retain users.

As Figure 10 shows, a range of these techniques tend to be employed in combination in a single system