

# **Time for Health**

## **Health Literacy Project Proposal**

### **DRAFT**

*“One can ‘deliver’ a parcel or a pizza, but not health or education.”*

Jake Chapman in the Introduction to his ‘System Failure – why governments must learn to think differently’, 2<sup>nd</sup> Edition, 2004, published by Demos

### **Vision**

A local network of active citizens and professionals creating healthy, vibrant communities, through better access to health information, opportunities to experience and practice the arts and to make a contribution to community life.

### **Aims**

- To enable doctors to carry out their duty of care to give health information
- To address inequalities in access to health information for individuals and neighbourhoods – health literacy inclusion
- To teach the skills of self-prevention, early diagnosis of problems and self-management, how to access and interpret health information for individuals and communities, making best use of GP consultation time, other health professionals, health support groups and other resources in the community
- To develop a broad-based health literacy service as a partnership between professionals in health, adult education, arts, multimedia, museums, libraries, the voluntary sector and trained volunteers
- To build local capacity to create true ‘healthy living communities’ and active health networks as an alliance between professionals and local people.

### **Summary of Proposal**

This paper outlines a proposal for a local health literacy service based around a GP surgery at the heart of a local healthy living network. This service creates a mechanism for GPs to ensure patients have access to quality health information in a professionally monitored environment. It allows the surgery gradually to play a dual role in the community as a centre for support to remain well alongside its conventional role in diagnosis and treatment of disease.

The service requires three professionals to act as bridges between health professionals at the surgery, patients and resources in the wider community:

- Health Literacy Coordinator (Project Manager)
- Arts for Health Coordinator
- Volunteer Time Broker.

(See Project Diagram – Appendix 1) These may either be new posts or make better use of existing staff who may be redeployed to embrace these roles.

The Health Literacy Coordinator acts as a broker for a set of relationships between health professionals, patients, their need for accurate health information and other opportunities to develop health literacy in the wider community. The Coordinator takes patient referrals and ‘information prescriptions’ from GPs and other health professionals and arranges for patients to have access to a range of opportunities to develop their health literacy, including written materials, visual aids, information technology, multimedia, the arts and volunteering. The Coordinator arranges for volunteer health literacy facilitators to be trained and manages the quality of their work. This post is directly accountable to and line managed by the GP practice and in turn acts as overall Project Manager and line manager to the other two posts.

The Arts for Health Coordinator is responsible for organising a range of opportunities for patients to experience and practice the arts through performances, workshops and exhibitions both in the surgery and in the community. This post is accountable to the Health Literacy Coordinator.

The Volunteer Time Broker arranges for patients to take an active part in healthy living activities, arts activities, health support and expert patient groups and for them to receive ‘time credits’ with which to gain Healthy Living Awards. This post is accountable to the Health Literacy Coordinator.

The whole project is overseen by a local Steering Group with representatives from the health and voluntary sectors.

### **What is health literacy?**

Short definitions of health literacy:

*“Health literacy is the ability to read, understand and act on health information.”*

Helen Osborne, Health Literacy Consulting, MA

*“Health literacy is the ability to make sound health decisions in the context of everyday life.”*

‘Navigating Health – the role of health literacy’ by Ilona Kickbusch, Suzanne Wait & Daniela Maag, p.4

HEALTH LITERACY means increasing patients’:

- Awareness of the variety of health information resources
- Access to alternative sources of health information, advice and guidance
- Ability to determine the quality and validity of information given
- Knowledge and understanding about health issues and treatments
- Guidance to self-management of health care and treatment plans

PATIENT EMPOWERMENT means increasing patients’ sense of ownership and ability to manage their own health through greater:

- Health literacy
- Participation in treatment decisions and health care planning.

*“Health literacy means more than being able to transmit information. It is about developing the skills to be able to acquire and read health information and successfully apply it to one’s own situation – whether this means making an appointment to visit a doctor, or adhering to a treatment regime.”*

From ‘Health Literacy’ – report by Saranjit Sihota and Linda Lennard for the National Consumer Council, 2004

*“Health literacy extends beyond these definitions and is a shared responsibility between patients (or anyone on the receiving end of a health communication) and health providers (or anyone responsible for communicating health information). Health literacy happens when patients and providers each communicate in ways the other can understand.”*

Helen Osborne, Health Literacy Consulting, MA, USA in ‘Health Literacy: How Visuals Can Help Tell the Healthcare Story’ at [www.healthliteracy.com/uploads/J\\_of\\_Vis\\_Comm\\_3-06.pdf](http://www.healthliteracy.com/uploads/J_of_Vis_Comm_3-06.pdf)

## **Why propose a Health Literacy Project?**

It is clear that doctors alone cannot make patients well. They cannot ‘deliver’ health. Health is a multi-way process of communication which is co-produced between doctors, nurses, other health professionals, patients, their families and communities.

General Practitioners have a specific duty of care to provide proper health information to patients. While some do this in the normal course of consultation, many GPs are failing to do so, either through pressure of time and resources, lack of interest or sheer negligence. This failure is currently leading to millions of pounds worth of successful litigation against the NHS through allegations of failure to provide proper information about treatments. Poor communications with patients are costing the NHS dearly.

Health professionals struggle to provide an adequate educational and information service without the resources to back them up. This means investment in state-of-the-art presentation of health subjects through multimedia designed with a range of learning styles and needs in mind.

It is worth remembering that the Wanless report into the future of the NHS outlined a vision of a future health service in 2022 in which: *“Patients are at the heart of the health service of the future. With access to better information, they are involved fully in decisions – not just about treatment, but also about the prevention and management of illness. The principle of patient and user involvement has become ever more important and the health service has moved beyond an ‘informed consent’ to an ‘informed choice’ approach.”* (Wanless Report, 2002, 2.10)

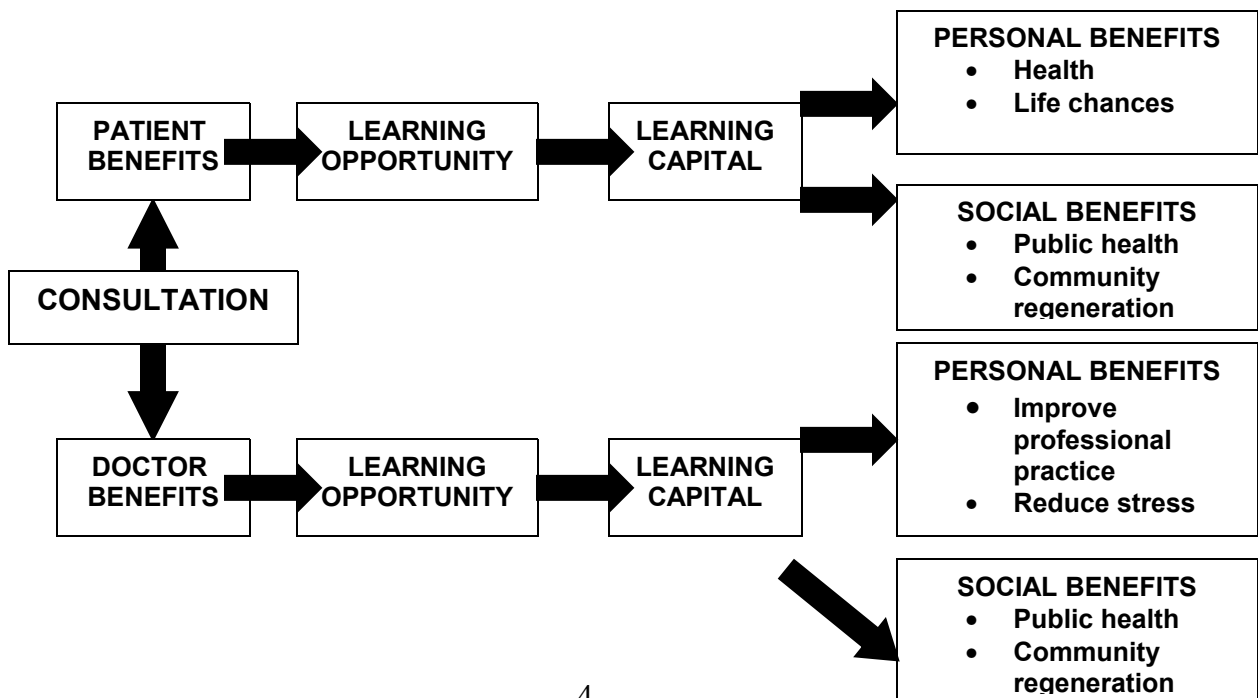
However, he showed us how far we have to go from the present reality to achieve this vision: *“The health service is not yet sufficiently patient centred. The Interim Report included survey evidence showing that patients commonly feel that they have insufficient involvement in decisions, there is no one to talk to about anxieties and concerns, tests and treatments are not clearly explained, insufficient information is provided to family and friends and there is not enough information about recovery.”* (Wanless Report, 2002, 2.21)

He then outlined three possible future scenarios for a future NHS: solid progress; slow uptake; fully engaged; and the potential costs and savings involved in each scenario. He describes the fully engaged scenario as one in which *“levels of public engagement in relation to their health are high”* and that *“The difference between the solid progress and fully engaged scenarios is a dramatic improvement in public engagement, driven by widespread access to information – for example, through media such as the internet and digital television.”* (Wanless Report, Chapter 3, Scenarios Summary & 3.20)  
 He estimated that the financial savings from a fully engaged public could be substantial: 30 billion pounds a year by 2022.

A growing body of evidence shows that when patients are fully engaged in decisions about their treatment and in managing their own health care they have a better experience. This results in more appropriate and cost effective utilisation of health services and better health for all. The key to patient engagement lies in building health literacy at the primary care level and ensuring that health care practitioners help patients to help themselves.

The GP consultation has benefits for both the patient and the GP and there are clear links between healthcare and both lifelong learning for individuals and community regeneration. Each consultation is a learning opportunity for both GP and patient which in turn builds up ‘learning capital’ which has both individual and community benefits.

### Health learning benefits of a doctor/patient consultation



Encouraging patients to take more control when they are ill is also an effective tool for improving public health. Paternalistic styles of practice tend to create dependency and undermine self-reliance. Promoting involvement and a sense of ownership of their health care could be the best way to ensure that people adopt healthier lifestyles.

The National Consumer Council carried out the first major survey of health literacy in its groundbreaking report of 2004 quoted in the box above. Amongst its total of 17 recommendations it pointed to the following areas of activity which support this proposal:

*“It is crucial that patients have access to material to inform themselves as, when and how they wish, and to use it in discussion with health professionals.”*

(Recommendation 5)

*“Research is needed to understand peoples’ information needs across the full range of health services with which they come into contact...”*

(Recommendation 6)

*“Information should be available in plain language, and should be developed through work with literacy and education providers to create materials that are educative and user-friendly.”* (Recommendation 7)

Health literacy and patient empowerment are a central part of any modern health programme. Evidence from the USA shows that the key elements of a successful partnership between service users and public service professionals are:

- individuals and organisations plugged into communities
- trusted sources of information and support
- professionals as peers working alongside service users.

Healthcare professionals talk about developing a “*prescription to end confusion.*”<sup>1</sup>

Doctors are currently the primary source of health information and advice.

This burden can be shared by health literacy facilitators.

### **A Role for Health Literacy Facilitators**

*“There is a sea change in prescribing. People are intuitively seeking non-medical alternatives in non-health settings. They need goals and creativity to make them feel like human beings again.”*

Elysabeth Williams, Senior Mental Health Promotion Lead Officer,  
Stockport Primary Care Trust quoted in  
‘Culture and Health – Building the Evidence’, Northwest Culture Observatory

Existing services such as health promotion provide crucial information services whilst health visitors and community nurses engage in face-to-face contact with people in their homes to reinforce these messages. However, these services are severely limited in their scope.

Creating effective health literacy across whole communities will require health care practitioners to diversify their practice to include the following:

<sup>1</sup> Evidence supplied by Gill Branch, nursing professional with experience of US system.

- delivering treatment which involves giving patients explanations about side-effects of medicines;
- involving them in decision making about their treatment;
- giving them advice on weight, nutrition and exercise;
- giving them counselling about emotional issues that might be affecting their health;
- and for those with chronic disease, giving them a plan to manage their care at home.

Many health care practitioners may object that they do not have the time to carry out these additional tasks of informing and educating. These new demands can be taken up by qualified staff providing a direct and personal service that can help people find, interpret, use and understand health information.

The Health Literacy Coordinator in this proposal would be a health care professional with expertise in information sources and how to access them and well developed critical appraisal skills. To support the process of explaining and shared decision-making they would also have excellent teaching and communication skills. Their role could include sourcing and interpreting a broad range of 'health information' resources, developing educational programmes, providing drop-in and one-to-one advice consultations, delivering group awareness sessions and identifying issues that cannot be easily answered to encourage further research. They would train local volunteer health literacy facilitators or 'Health Helper' community health advocates and manage the quality of their work.

With the establishment of a health literacy service, patients would be given the option to consult the health literacy facilitators instead of their doctor if information was all they required, or they could be referred to them by their doctor for more detailed information following consultation. The health literacy facilitators would reduce the demand on doctors' time and the information patients receive could be seen as part of a therapeutic package, with doctors 'prescribing' information in the same way they prescribe medicines.

The job of the Health Literacy Coordinator in this proposal is to act as a bridge between health professionals and the health information or literacy needs of patients.

The Coordinator is the central hub for referral to a range of activities and opportunities:

- trained volunteer health literacy facilitators who can in turn refer patients to appropriate sources of information and activities
- clear written, visual and aural materials and aids using multimedia, information and communication technology in partnership with museums, libraries and adult education services
- health support and expert patient groups
- arts opportunities c/o the Arts for Health Coordinator
- community volunteering opportunities c/o the Volunteer Time Broker.

## Arts for Health

*“My vision for the arts and health work is that the art should have the space to speak for itself and that exemplar projects should be embedded in the strategic development process.”*

Polly Moseley, in ‘Culture and Health – Building the Evidence’,  
Northwest Culture Observatory, p.12, 2006

There is an increasing recognition that the arts have an important if not vital role to play in healthcare. The National Network for the Arts in Health defines four areas where the arts and health overlap: (see <http://www.nnah.co.uk/whatis.html>)

1. Arts in healthcare settings – for instance in GP surgeries
2. Community Arts in health – using the arts to deliver health promotion messages in the community
3. Medical Humanities – using the arts to assist the education of medical professionals
4. Arts Therapy – usually personalised use of the arts as part of therapeutic treatment.

Pioneers such as the Withymoor Health Hive in the West Midlands during the 1990s have shown how the arts can be integrated into the normal practice of a surgery with writers in residence, artworks in the reception area, drama in local schools and the community ritual of an annual torchlight procession – all with explicit or implicit health education messages. *“The whole purpose of working with arts people was for me that they can and do encourage conversation. Health literacy is best passed on by people talking with each other...Arts people too can create an environment where it is OK to ask questions, an environment that encourages learning from others, from text, from videos and films, where people can be respected even though they ask foolish (to the health professionals) questions.”*

Personal email from Dr. Malcolm Rigler, organiser of the Withymoor Health Hive.

Another pioneer has been the Bromley by Bow Healthy Living Centre in London where art has been a central theme since its inception 20 years ago.

*“When the new purpose built Healthy Living Centre was being developed, integrating artists into the new Health Care team breathed new ideas and proposed new solutions to tackling health related problems. Artists helped to create the very special physical environment of the Health Centre. For example, the courtyard garden with its fountain and sculpture welcomes patients and visitors on their way to reception and provides a tranquil oasis in the noisy inner city... Frank Creber, the painter in residence, describes how art works at the Centre: ‘Art gives people the chance to respond to their unique situation’ ... By engaging in creative activity people gain the knowledge that they can alter the world through their own activities. To make an image requires making judgements. As artistic skills are developed a growing sense of competence is also developed along with the realisation that the world is open to change for the better.”*

Posted by Libby Brayshaw at Global Links Initiative,  
<http://www.glinet.org/inspiredetail.asp?id=337&CatID=330>

A powerful editorial in the December 2002 edition of the British Medical Journal argued that we should spend slightly less on health (0.5%) and more on the arts: *“If health is about adaptation, understanding and acceptance, then the arts may be more potent than anything that medicine has to offer.”* (BMJ Editorial 2002;325:1432-1433, 21 December, Richard Smith)

In a response to this editorial, Jane Macnaughton, Director of the Centre for Arts and Humanities in Health and Medicine (CAHHM) at the University of Durham, says: *“We hear from patients that what they get from engaging with artists is a sense of their own creative worth. The artist views the patient as someone with the potential for creativity; the doctor regards the patient as a problem to be solved. Artists will point to the quality of the work produced by those who participate in their projects as evidence of success.”*

Others have pointed out the role of the arts in building stronger communities: *“What used to be understood as the preventative approach to healthcare is increasingly about building capacity for change, externally in developing social capital and internally in improved training and holistic approaches - approaches that the arts can help define and contextualise.”*  
(‘From Ice to Fire – Arts in Health for Social Inclusion’  
by Mike White and Mary Robson, Centre for Creative Communities.)

The Northwest Culture Observatory is highlighting best practice in this area with its recent publication of ‘Culture and Health – Building the Evidence’ which is full of case studies of the effects of the arts and media on health.

The essence of all of these activities and critiques is to see healthcare itself as a blend of science and art. A happy marriage of ‘the arts’ with medicine in a local context can only add value to the processes of healthcare. This means that the arts are not seen as some cute add-on to the practice of healthcare but that thoughtful professionals work out creatively together how the whole experience of healthcare can be ‘humanised’ and made more meaningful for patients, from the appearance and subliminal messages given by the healthcare venue to the attitudes and practices of the healthcare professionals.

*“Perhaps the most important reason why the role of the arts is central to a successful health literacy project is the arts help us to see things – including our own roles – in new ways.”*

Personal email from Dr. Malcolm Rigler, organiser of the Withymoor Health Hive.

The proposed project sees an Arts for Health Coordinator as absolutely integral to the design of a meaningful health literacy service with a deeper and wider impact in the local community. This person would bring about creative uses of the arts in the healthcare setting of the GP surgery and in the surrounding community. It may be an existing community arts post that develops a closer relationship with the GP surgery or a new post. The post must be seen as essential to the health literacy mix rather than ‘the icing on the cake’.

## Health Volunteers

If health professionals cannot alone deliver health to patients then clearly patients must play a greater role in their own healthcare or wellness. Health must be ‘co-produced’ in partnership and all skilled health practitioners know this. The ‘fully engaged’ health service described by Wanless will never become a reality without a radical change in the relationship between patients, their own health and health professionals.

We need to think beyond the narrow confines of a ‘medicalised’ model of health and wellbeing to a perspective which takes in the whole community and its resources. This might be described as an ‘asset-based’ rather than ‘deficit-based’ perspective. In other words we make better use of existing resources which we know can help people to improve their health. A crucial part of this scenario is the effort of unpaid volunteers in creating a healthy living network of active citizens engaged in health literacy, information, arts and community activities.

This giant untapped resource needs first of all to be recognised for the underused asset that it is. Second, we need to regard this effort as ‘work’, essential work in creating a healthy society. Third, this work should be rewarded, not with monetary payment but some meaningful ‘thankyou’ from society. One way to do this is through the mechanism of a ‘time currency’. This is sometimes known as a ‘complementary’ currency that acts alongside money and simply offers people local ‘time credits’ for each hour of work they give to the community. Every activity that requires work to grow the healthy living community can be rewarded with time currency and each time credit exchanged embeds a set of values into community life: treating people as assets, valuing peoples’ work, reciprocity and respect for each other. People use their time credits to gain services or rewards from others in return.

This idea began in the USA in the early 1980s when Edgar Cahn began promoting ‘service credits’, later rebranded as Time Dollars. The idea was imported to the UK in the late 90s in the form of ‘time banks’. Time banks have now proved themselves to be valuable tools for community development and rebuilding trust in communities in diverse ways – through work with young people, adult learners, community social events and celebrations. Such approaches have been applied to the health sector in various places such as the Rushey Green surgery time bank in south London.

One US doctor involved in time banking has compared the operation of the human heart and the circulation of blood with the operation of currency in healthy communities: *“The core economy, the heart economy of a community, sustains the connective tissue of human bonding holding a group of people together”* and *"the currency of the heart is the most powerful electromagnetic force in a human. A healthy heart meets needs."*

Needs of the Heart and the Bank - Transfusing a weak society with complementary currency, article by Dr. William T. Evans available from [www.timebanks.org](http://www.timebanks.org)

In this proposal a paid Volunteer Time Broker organises the time bank by connecting up people willing to give their services with the health-related rewards they would like for their involvement. Volunteers can act as the trained health literacy facilitators and 'Health Helper' community health advocates described earlier, organisers of health support and expert patient groups, artistic activities, exhibitions, social events, community celebrations and other community activities. Rewards such as trips, social events, healthy food, vitamins, exercise equipment may all be offered to motivate new volunteers to get involved.

## **Project Development Strategy**

The project should be conceived with distinct developmental phases in order to ensure adequate planning, resourcing and networking of the proposal, maximum participation of key stakeholders and evaluation of impact.

We suggest four distinct phases: Development, Delivery, Evaluation, Follow-up

### **Development Phase**

- Appointment of Project Steering Group with representation from GP surgery, local health board, voluntary, arts, libraries and museum sectors and a university.
- Outline scoping of key questions including:
  - What will the service offer: information, advice and guidance, referral, consultation, education & training, facilitation?
  - What are health information, health promotion, treatment and care, complementary therapies, support groups, healthy living, community health initiatives?
  - What information sources exist and how should these be assessed?
    - what it is – subjects covered
    - how it is presented – formats – written, visual, auditory
    - who sees it – audiences eg young people, elderly, mental health etc.
    - where it is presented - list of venues
    - when it is presented – on prescription, on request.
  - Evaluate current sources of information: National Electronic Library for Health, NHS Direct Online, Doctor Patient Partnership Publications, commercial information providers, voluntary organisations?
  - If education programmes are to be provided, how will these be developed?
  - What links can be made to existing health and information programmes?
  - What links can be made to existing community arts programmes?
  - What scope is there to develop a volunteer programme or health-based time bank to support the project?
  - How will the health literacy facilitators be trained and deliver their service, from where, at what hours?
  - How will the service be governed, and by whom?
  - How will the service be managed, and by whom?
  - Who are the healthcare professionals that this service will work alongside?

- What does an information prescription look like and how will it work in practice?
  - What training will healthcare professionals need to make use of the new service effectively?
  - What scope is there to engage the adult education, museum and library services in promoting health literacy and providing materials for use by health literacy facilitators?
  - How will the service be marketed to the wider public?
  - What will the service cost?
  - How will the service be sustained beyond start-up grant funding?
- Appointment of consultant to do feasibility study based on scoping questions
  - Appointment of three principal officers (fulltime) or redeployment of existing posts:
    - Health Literacy Coordinator (Project Manager)
    - Arts for Health Coordinator
    - Volunteer Time Broker
  - Appointment of Special Adviser – 2.5 days pw
  - Start awarding time credits to patients and non-professional participants in setting up project.

#### **Delivery Phase**

- Build in monitoring and evaluation from day one (eg local university)
- Three principal officers work as a team, meeting regularly to discuss progress and manage the project – Steering Group acts as reference group for governance and management issues
- Volunteers rewarded with time credits and rewards

#### **Evaluation Phase**

- Full evaluation of project by a university research team
- Evaluation widely disseminated

#### **Follow-up Phase**

- Plan follow-up project, learning lessons from evaluation and adopting most cost-effective model for future Health Literacy Project
- Lobby NHS for support to selected GP practices for ‘enhanced services’ in national pilot.

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**John Rogers**

**Value for People**

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