

circles of Care

A new approach to healthcare based on social networks

Indri Tulusar





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Research partners Research partners

#### **Research partners**

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## pmuk



The research project is a collaboration between the Helen Hamlyn Research Centre at the Royal College of Art and two industry partners, healthcare product designers Pearson Matthews and mobile network company Orange.

The Helen Hamlyn Research Centre was set up at the Royal College of Art in January 1999 to alert design and business to the far-reaching implications of a rapidly changing society. It works to advance a socially inclusive approach to design through practical research and projects with industry. Its Research Associates Programme teams new RCA graduates with industry partners. www.hhrc.rca.ac.uk

Pearson Matthews is a design consultancy that for many years has focused on healthcare, believing that design has a great deal to offer when used to make connections between individual, commercial and social needs. Their strategic futures thinking is matched by their proven ability to deliver – taking research and developing it through to ground-breaking products. www.pmuk.com

The Orange group is one of the world's largest mobile communications companies and a subsidiary of the France Telecom group, with operations in 19 countries across Europe and beyond. It provides a broad range of personal communications services, including Orange GSM1800 services and other digital cellular telephone services. www.orange.com

#### About the author

Indri Tulusan is the daughter of two doctors and has always been fascinated by how the body works. She initially studied medicine in Germany, where she grew up, before taking up product and furniture design at Kingston University. Understanding patient contact and dealing with basic human needs proved an excellent foundation for her under-standing of human behaviour and her subsequent interest in interaction and experience design for well-being.

In 2001 Indri graduated from the Royal College of Art with an MA in Product Design. Her final project about a mobile technology service (entitled >olu) won the College-wide Lattice Award for Sustainability. During her studies, Indri's project IntelliSkin (developed with Kelly Sant), wearable biomedical screeners, won the Kenny Yip medical innovation award and received sponsorship from Orange.

Indri has worked in design research for major companies such as Philips and Nokia. She is also active in international research conferences such as Doors of Perception in Bangalore, where she presented a project titled Wandervogel, developed at the Helen Hamlyn Research Centre with research partner Cityspace.

Her work with her design practice Teko has received national recognition from NESTA and D&AD, and she has just completed a second Helen Hamlyn Research Associate project with Pearson Matthews and Orange. This book is the outcome of that study. °7

#### **Executive summary**

The Circles of Care project began with the question: what role can communication and self-monitoring technologies play in helping people maintain a proactive approach to their health and well-being?

The study was set in the context of western economies struggling with escalating healthcare costs and growing calls for a paradigm shift – from a system that simply treats ill patients to a model for health services in which the focus is on prevention rather than cure.

The study took an experience design research approach to investigate, first, what needs people have in maintaining their health. It compared different health models to analyse how they give the patient a passive or an active role.

Using design ethnographic techniques, the project conducted a cross-cultural analysis of individual attitudes to maintaining health by focusing on a user group of 20 people (ten in the UK, ten in India and Italy) who have recently moved to a new town or country. Displacement was used as the common element. This enabled people to focus on the relationships that support their health beyond self-reliance.

The findings of this research revealed that people have three universal requirements to support their own health: fitness of body, autonomy of mind and relatedness to others. The value of relatedness (being supported by a social network) and the need for trust were more apparent in India, but were also strong factors in the personal experiences of other nationalities.

From the research findings, the study established the proposition that, there is an 'inbetween' space between self help and the expert help of medical professionals that has received relatively little attention from designers, manufacturers, service or social providers.

This is the social network of friends, family, work colleagues and neighbourhood facilities such as health food shops and fitness centres which operates alongside the GP or hospital professionals in helping us to maintain our health. The project has identified the social network as a complementary healthcare model and given it a name: Circles of Care.

The outcome of the project is a map of the space inbetween self help and expert medical help, which shows how we build, adapt, share and pass on our personal health network. It is a way of thinking about healthcare as a social activity as well as a the medical one. How these needs are changing is illustrated in different life stages.

This publication explores the opportunities offered by Circles of Care. It outlines the concept and defines its players, activators, experiences and emerging user needs. It identifies an area for development and indicates how networked technologies can activate solutions within it. It demonstrates the potential of approaching the shift in healthcare from an experience design viewpoint.

The outcomes are presented as a service landscape. Within this framework key life stages are mapped against health needs and opportunities for developing social networks to address them. This is supported by scenarios – eight narratives are illustrated in this report – suggesting how this landscape can be mined for new service opportunities linking private, public and voluntary sector organisations in new partnerships.

#### **Benefits**

Individuals already create their own wellbeing strategies with the help of family, friends and work colleagues before going to the doctor. This model offers the possibility of support platforms to encourage these social health networks.

For network providers, the model can be used to develop services which are closer to the consumer at key life stages. The social value of these services will build brand loyalty by fostering a sense of partnership between service provider and customer at key points in the life course.

For retailers and medical product companies who make up the supply chain, there are business opportunities in understanding and meeting the needs of consumers who are responding more proactively to their Executive summary Executive summary

own health needs. Circles of Care implies a move beyond self-monitoring and selfdiagnosis products, which has grown rapidly in recent years.

For voluntary sector organisations, the opportunity to build a partnership with a network provider as part of a social network can extend their role from fund raiser to service enabler.

For the NHS, the study shows how growing new social models of well-being could become an important adjunct to the existing system.

#### A beginning

New service concepts support a social network of care at different life stages. These will emerge by exploring the landscape in more detail with the different players who could enable them.

The Circles of Care concept approaches health as a social activity and marks the beginning of a healthcare system based on social networks in which individuals take an active role in their health and the well-being of those close to them.

The service narratives aim to create conversations about the opportunities for all the different public, private and voluntary sector players. In this context the designer can take the role of mediator between the players, making all aware of evolving user needs.

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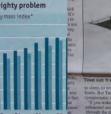
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BURGERS, crisps and fizzy drinks could be subject to a 'fat tax' under plans to deal with Britain's obesity epidemic, it revealed vesterday. A report by

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#### Introduction

#### **Cure or prevent?**

The crisis of healthcare systems is an ongoing issue, especially in European welfare states. In the UK we currently have a system where we wait for people to get ill before we treat them. The British health model is still based on cure, by destroying the sickening force. The ideal patient follows the expert's instructions without dispute.

This is similar to a child's health being the full responsibility of its parents.

However, people are now becoming more responsible for maintaining and monitoring their own bodies. Hence the growing movement towards self-care and personal well-being. Increasingly we look to social networks of support before going to the traditional expert system. But this social network currently receives little attention from design and industry.

#### How are you?

As individuals, we are becoming increasingly proactive with regard to our own health. How can products and services address this?

Developments in information technology can give individuals more opportunities to inform themselves about health issues. The use of internet, mobile technologies, self-test biomedical products and genetic tests are just a few examples of new technologies that can help individuals create 12°13 Introduction Introduction

and sustain their own personal healthcare networks.

"According to recent studies, 52 million Americans, or 55 per cent of those with internet access, use the internet for health and medical information. Half of these people say the information they garner on the web has improved the way they take care of themselves, and 36 per cent say it has affected their decision on behalf of a loved one." (Zuboff S, 2004)

These trends suggest that people want to live their lives more proactively, particularly where health is concerned.

#### **Designing for social networks**

When looking at new markets, one important challenge is to consider the long-term effects on behaviour and the different service opportunities that might evolve as a result.

The designer's role is to consider this long-term relationship between users and services and bring it to the attention of the various parties involved (such as business, public sector and the general public).

For that reason, the research approach is sited in the field of experience design and service design. Experience design deals with how products are experienced over time. Service design deals with how these experiences are organised within networks.

## < These trends suggest that people want to live their lives more proactively, particularly where health is concerned. >

New, proactive health consumers need new platforms to support them. How does this research investigate these new social networks?

First, it investigates the different strategies and experiences of users building their own social networks of health, and sets out the concept of Circles of Care to identify these strategies and experiences. Second, it proposes a complimentary healthcare model or landscape where user strategies and experiences can be supported, for instance by emerging technologies. The concept of Service Narratives is used to envision this new health landscape. Circles of Care and the Service Narratives within, provide the framework for designing for social networks of health.

In this project design is used as a research tool - as a way of creating awareness of new social trends, and as a way of answering questions about technology, how we perceive it and how we can benefit.

#### Research

#### The research map

Four different areas were explored to investigate the proactive health consumer:

Current health models People inspired design Communication technologies Cross-culture inspired design

#### **Current health models**

These were examined by comparing the western health model of cure (responsive) and the eastern health model of care (proactive). For example, the Indian or Chinese model is based on prevention by strengthening the vitalising forces. The doctor serves the patient and the patient is active and instrumental in his or her own health. In most western health systems, the medics are waiting for people to get ill.

This area was studied through literature (sociology books, articles and internet) and medical expert interviews.

#### People inspired design

The study began with an analysis of individual attitudes to maintaining health by focusing on a group of ten people based in the UK (aged 20-40). They had recently moved to a new town or country, necessitating the creation of a new circle of care. This was extended with ten more people between 40-65 year of age who have not moved recently.

#### **Communication technologies**

The research explored how new communication technologies can play a role in building this personal healthcare landscape. For example, people were interviewed about what technologies they use for their health routines. They were asked if they have any self-diagnosis products at home, if they use the internet, or any other technology to check on their health issues.

#### **Cross-culture inspired design**

To compare attitudes to health in different cultures (design ethnography), the research was extended by interviewing fifteen more people in Italy and India. Italy was chosen because of its strong family networks; India because of the interesting mixture of alternative health systems alongside the mainstream systems.

#### The main research questions

How do people maintain their health? What kind of prevention routines exist? What sort of networks do people have? How do these differ between cultures? < This desire for choice within a broader spectrum of health systems is a growing movement in the UK. >

#### Why design ethnography?

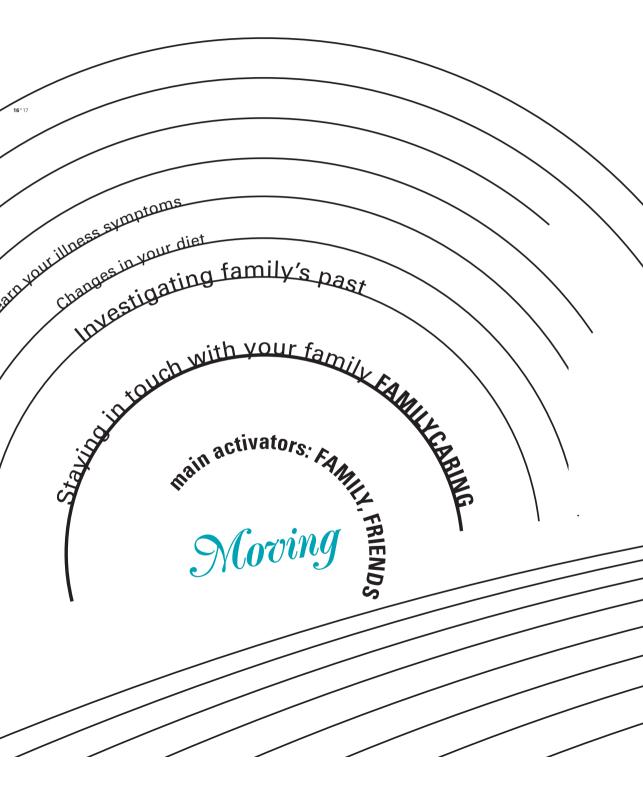
This cross-cultural comparison was used to construct a design ethnography interrogating individual attitudes to health. It gave not only an insight into their cultural view of themselves, but also indicated larger social changes.

For example, it was apparent that people whose background is from a more collectivist culture, like Asia or Italy. naturally kept in touch with family, and used home remedies or alternative medicines as part of their well-being routines. This desire for choice within a broader spectrum of health systems is also a growing movement in the UK and North America. A study in the Journal of the American Medical Association found a 47 per cent increase in the total number of visits to alternative medicine practitioners between 1990 to 1997, from 427 million to 629 million. This was also found to be widely distributed across all socio-economic groups.

These ideas from other cultures, about health and maintaining well-being, were fed into the project inspiring new models of interaction.

This design process of using ethnographic data to generate new technology and business ideas is also called 'ethnographic imagination' or 'contextual invention' (Hewlett Packard, 2003). The challenge is to make explicit the assumptions, premises and narratives that are hidden beneath what people think, feel and do (Diener E, 2003). Showing what appears to be so natural and just taken for granted, in any culture-specific context can form the basis for designing new systems and services.

This ethnographic observation brings significant stimulus and insight to the design process, extending beyond that based on personal speculation or statistical data.



#### Research Research

#### Displacement

Displacement was used as a critical factor to identify people who developed new Circles of Care out of necessity. People *Moving* to another city or country, travelling frequently or commuting between work and home were considered as experiencing different forms of displacement.

#### The main research tools

Expert interviews with traditional and alternative medics and sociologists. User interviews were conducted to measure individual attitudes to health. Workshops with designers were held to discuss new approaches in depth. Using film as an inspiration to envision future health systems.

#### **Expert interviews**

Five health centres and five Doctors were visited in the UK, India and Germany. All were asked about their personal and professional view on health, in four specific areas: the benefits of their practice and approach; the shift in healthcare; the role of technology in healthcare; the role of proactive health consumers. Where appropriate, their facilities and approaches were evaluated and documented first hand. A selection of interviews is documented below.

#### Example one

A renowned Aryuvedic medical health centre in Bangalore was visited. The head

doctor was interviewed and his facilities were documented in detail. He had 25 years of practice experience. His patients (who he described as customers) were from and included both families and individuals. He explained that his Ayurvedic practice was complementary to other medical systems but the main difference is it offers two kinds of treatments: wellness care and illness cure. It encourages wellness care and advises people to lead a proactive lifestyle.

#### Insight

This ilustrates the shift in viewpoint between east and west, from responsive cure to preventative care through holistic treatments.

#### Example two

A General Practitioner (GP) in Germany with 30 years of practice experience was interviewed. His patients included all age groups. He stated that the rise in access to medical information through internet health sites was a nightmare vision for him. In his view 'pseudo expert' users create more pressure for medical professionals, since they do not have to rely on them for diagnosis and do not take everything they are told for granted.

#### Insight

This illustrates how patients go to their doctors more informed (or disinformed) about their health problems than ever before.

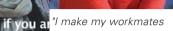


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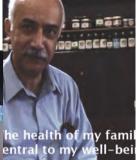
ou at "I make my workmates go to the gym with me."

"Health is being in contact with the people I love."

phone a friend







"My brother and me are

food freaks."

Example three

A GP in London with 20 years of practice experience was interviewed. His patients included all age groups. He stated that his patients are mainly passive and he tries to inform them with leaflets and advice to a more preventative life style. He welcomed the change in access to healthcare information to help the overloaded national health system. For instance he recommends patients with repetitive strain injuries (RSI) to initially check a website set up by a self-help group, www.rsi.co.uk. He asks them to only come back to him if they do not get suitable help from there as the waiting time for the physiotherapist is currently nine months.

#### Insight

This shows that medical experts use new ways to access healthcare information and are encouraging people to be more active.

#### **User interviews**

The initial group consisted of people aged 20 to 40 who had recently moved to

another city necessetating the construction of a new circle of care. This was extended to include another sample group of people aged 40 to 65 years old. In all, 20 people of different nationalities within the UK and 15 people in India and Italy were interviewed to compare cross-cultural approaches.

People were asked to give their personal viewpoint on four areas to do with health. Short films were made from the interviews and used as a tool to illustrate the Circles of Care concept.

*The first area* addressed their general attitude to health. People were asked: "*How would you define being healthy?*" "*Do you have a routine to prevent illness?*"

*The second area* interrogated personal health strategies. People were asked, for example:

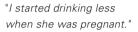
"What do you do for your daily well-being?" "What do you do when feeling unwell?" "Who do you speak to?" "What do you eat or drink?"



I call my mum for ext advice



"I drink warm water every day."



*The third area* investigated primary motivators for routines. The interviewees were asked:

"What motivates your health routines?"

*The fourth area* looked at the use of technology in health issues. For exapmle the participants were asked: *"Do you check or treat yourself for something regularly?" "How do you check it?" "Do you use the internet for health matters?"* 

Interview insights There were two initial reactions to healthconsciousness:

"I am not health conscious." Although one group of people initially denied being health conscious during the interview, it became apparent that they all had a certain health routine and also a circle of care, even if they were not fully aware of it.

*"I am very health aware." These* people directly mentioned a specific health-related

strategy or routine:

An eating routine, such as eating "colourful food" and "self-cooked meals" to ensure a good balance and quality.

A physical routine, such as going to the gym several times a week, yoga or "running when feeling down".

An emotional reassurance routine, such as talking to family or friends regularly.

Their answers also highlighted other aspects. For example, education, family habits and cultural background were important. Disruptions such as moving or illness were seen as primary motivators for a change in health routines. Almost everybody had strategies to avoid visiting the doctor and relied on advice from other people instead. In this case, trust was an important factor. Healthy friends encouraged a healthy routine.

Most people had the equivalent of 'selfcare manuals', practices and prescriptions developed over the years from their own experience and networks.

#### Workshops with designers

*Doors of Perception (Bangalore, India)* The first workshop brought together ten service designers, product designers, technologists and social scientists to look at how people maintain health and what technologies are used.

#### Interaction Design Institut (Ivrea, Italy)

The second workshop was joined by 20 students and five senior design researchers. This looked more specificly at service design and designing for communities in the context of healthcare.

The key words that emerged from both workshops were control, responsibility, trust, motivation, holistic, change in life. The importance of an individual's self-help manual was emphasised again.

#### Research partners (London, UK)

A workshop with four senior designers of the medical product innovation team at Pearson Matthews, the international research manager from Orange and two researchers from the Helen Hamlyn Research Center discussed the Circles of Care concept in depth.

The participants took part in an exercise to reveal their individual circles of care using a cultural probe. They were invited to draw on a rubber glove, describing the people, objects and strategies related to their own well-being. (see page 20) This exercise made everybody explicitly aware of their own health routines. The main insight was that different life stages require different circles of care. Participants could identify with, for instance, being the head of the family where the health of the family as a whole is the overriding concern.

#### Film as envisioning tool

Feature films were used as an inspiration to envision future health systems and to present concepts about healthcare in a narrative way. These stimulated discussions at the beginning of the project and were used to demonstrate what a circle of care could look like.

'Gattaca' (Andrew Niccol, 1997) was used to illustrate an extreme future of genetic technology and its social implications. 'Fight Club' (David Fincher, 1999) was used as an example of a society with extreme self-help groups.

'*Memento*' (Christopher Nolan, 2000) illustrated radical survival strategies for everyday life when dealing with a chronic condition.

'*Amelie*' (Jean-Pierre Jeunet, 2001) was chosen to show disruption in everyday life.

< The research identified a need to reveal unarticulated consumer concerns and create ways to talk about and share them. >

Research Research

#### Conclusions

People create their own self-care strategies and increasingly rely on personal support networks before or after going to the doctor. People have circles of care but are often not aware of them.

The space between self-care and expert medical care needs more attention from service providers, designers and other agencies.

The research identified a need to reveal unarticulated consumer concerns, and create ways to talk about and share them. The design response is presented as a new landscape of care: a map of interrelated circles of care, extending through the life course and centred on key stages and life events. "Imagine your hand is a blank map of your circles of care. Where are your healthy things, people, objects, strategies, disruptions, motivations ? Take a pen and draw your circles of care on the next page."

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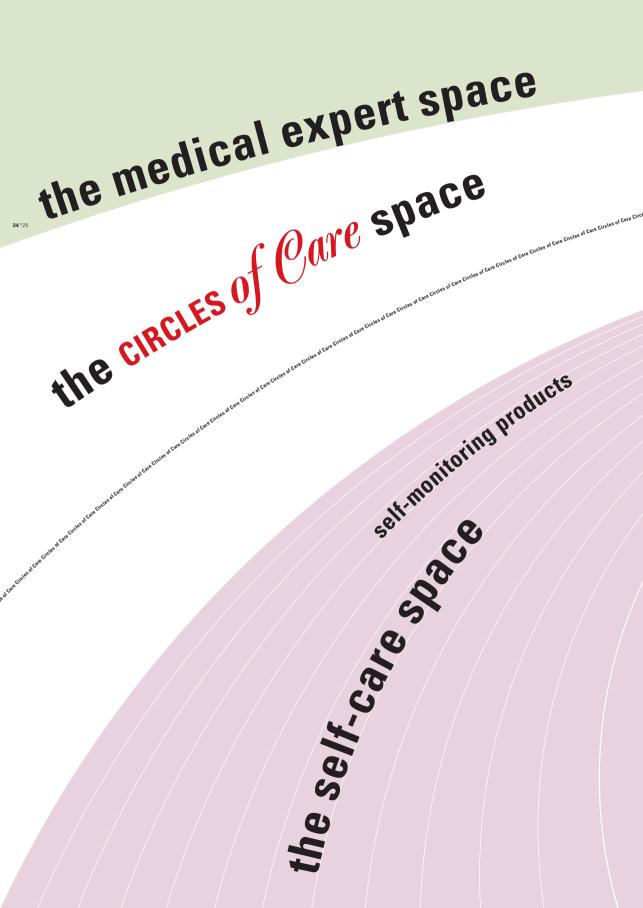
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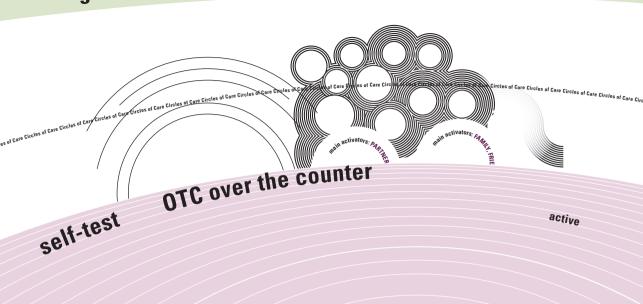
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DRAW YOUR CIRCLES of Care!



## government NHS private healthcare

patient



#### The landscape of care

The research takes three spaces of care: the self-care space, the medical expert space and the Circles of Care space.

Self-care is the closest space to one's personal health. In the self-care space, self-monitoring devices and self-diagnosis kits are used to keep track of your health conditions like diabetes.

At the other end, is the medical expert space where public and private health institutions, like the national health service (NHS) sit.

Circles of Care is the space inbetween self-care and the medical-expert space, where people are creating their own well-being strategies. In your circle of care your partner, family, friends and neighbourhood help you to maintain your daily health and well-being.

These personal well-being networks are

constructed from a person's experience and contacts. These experiences heighten general awareness of health and *require* greater levels of support, especially in growing a social network of personal care.

These social networks of personal care are the Circles of Care.

In the following pages the Circles of Care approach is explained using the concepts of relatedness, life events and activators. The outcome is a map of the Circles of Care space, which illustrates this new landscape.

#### **Circles of Care are based on relatedness**

The first phase of the project revealed that everyone has three universal requirements to support their own health.

#### Physical (your body):

"I like the way it makes me feel when working out or eating healthily." Autonomy (your mind): "Health is having control over my life, being The gym as a family concern. Health is seen as a part of your social network and not as a single activity. Picture taken in Bangalore, India.

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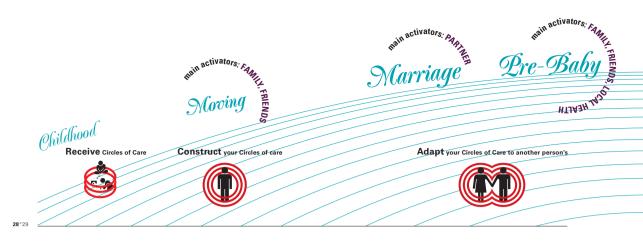
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able to do what I want to do." **Relatedness (your social network):** "Health is being connected to people I trust, the feeling of being supported."

People search for control (autonomy). This tendency of wanting control is seen very clearly in the rise in the number of people using self-care products to monitor and diagnose themselves in their own homes.

These self-care products are often bought because of a recommendation from someone trusted, who has used it before. This need for trust is a given in building a social network (relatedness) and is the main driver for constructing personal circles of care. For example, a sporty family member, a 'health freak' friend, or a workmate may influence your health strategies and so become part of your network of health.

Stimulating, extending and supporting social networks of health that are based on trust became the central focus of this research.

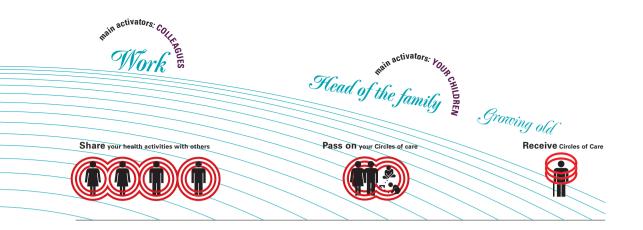
#### **Circles of Care and life events**

An individual's own culture and experience emerged as central to constructing strategies to support well-being. Your sociocultural background, family, education, friends and also disruptions in your routines such as illness, moving, ageing and having children, all influence your circle of care. These factors can motivate you to take responsibility for your daily health.

The research identified six different stages or life events where circles of care change or evolve. These stages are the main milestones of receiving, constructing, adapting, sharing and passing on one's circles of care.

*Childhood:* you are mainly dependent and a receiver of others' circles of care.

*Moving:* any period of moving to live in another place implies that one has to build new circles of care.



*Marriage + pre-baby:* in this specific life event you have to adapt your circles of care to take on other people's networks for example your partner. This became evident in the inteviews when both partners "got fit together for marriage" and when she was pregnant, her partner also started to drink less to motivate them both.

*Work:* work colleagues and social relations within the workplace are an important part of our circles of care. At work, people's routines and well-being strategies are often shared (ways of avoiding repetitive strain injury or back ache) with colleagues.

*Head of the family:* becoming the head of a family means taking on responsibility for other people and passing on circles of care to the whole family.

*Growing old:* as you grow older your circles of care become more dependent on other people and external agencies.

#### **Circles of Care Activators**

Circles of Care Activators are people who can play an active role in your circle of care. These include your family, partner, friends, neighbourhood and work colleagues, among others.

#### **Main activities**

Our individual health and well-being depends on building and maintaining circles of care. The main activities are to motivate and to activate health routines and also to monitor and screen your health.

**FAMILY CARING:** the family members take care of each other. Children monitoring their parents and parents motivating their children are examples of activities within circles of care.

**PARTNERING:** partners motivate and monitor each other because they share their circles of care all the time. This activity includes monitoring each other's diet, exercising together and managing stress levels or mood.

*Friends Coaching:* friends motivate each other in a reciprocal way. Certain routines that require extra motivation, like going to the gym regularly show how friends can create networks of health coaching.

*Semi-expert friend:* groups of friends who can deliver semi-expert advice about a health problem on the basis of

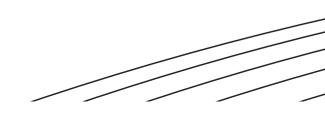
a relationship of trust.

*Peering:* colleagues who share the same work routines and similar health conditions. Hay fever or RSI are chronic patterns that create peering networks of help.

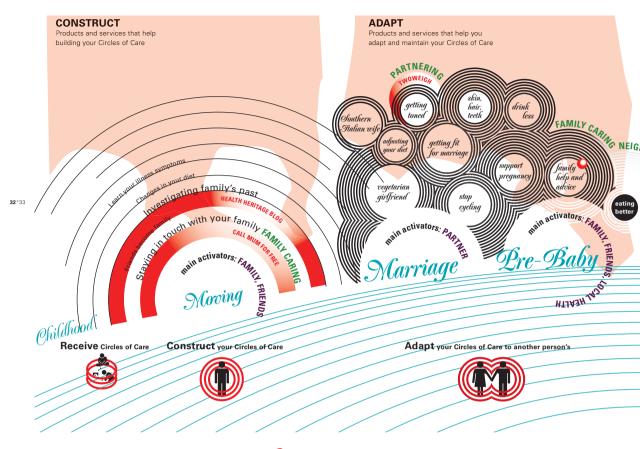
*Neighbourhood health:* the area where you live plays an active role in your health routines.

#### Map of the Circles of Care space

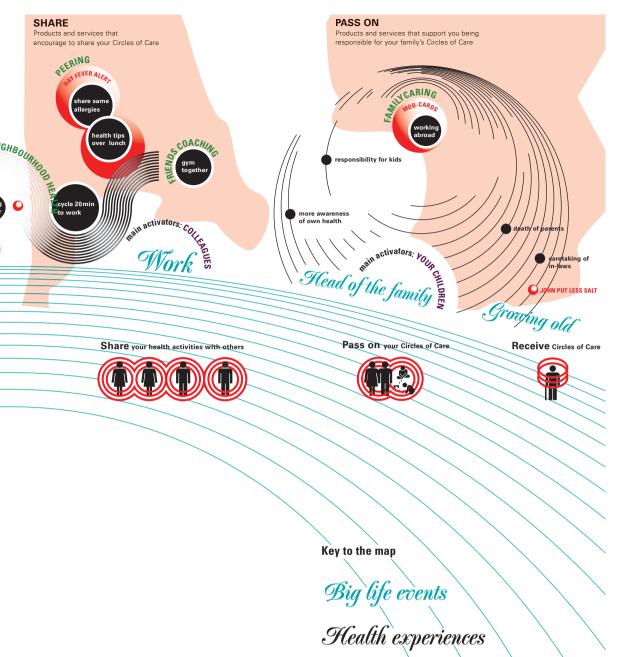
The map on the next pages shows a more detailed network of care points, based around health activities, which provide a local and people based network. Services can create a supporting structure around the individual. There are opportunities for each life event.







Map of the **CIRCLES** of Care space



**ACTIVATORS** 

**ACTIVITIES** 



**SERVICE NARRATIVES** 

HEALTH as a social activity

34°35

The Circles of Care model and the idea of health as a social activity explore an area previously unnoticed by most of the western health systems – yet it is experienced to greater or lesser extent by individuals within these countries.

The research suggests that most people have some form of supportive network, "spheres of support" or Circles of Care. These circles are not solutions for health but networks that have to be built, shared and maintained. The framework where the well-being strategies take place is social activities, for example, friends coaching or partnering. These networks are built on trust and the research identifies different activators of trust in different life events.

The key to opening up opportunities for these networks lies in understanding what health means at a personal level. Rising healthcare costs and a shortage of staff, combined with users becoming more and more demanding, are all creating a financial burden on conventional healthcare services and the NHS. This is where services that support Circles of Care at a consumer level can offer significant benefits. This is especially so with networked technologies, where the value comes through connectedness and sharing. As a consequence, such services can play an important role and respond to changing user demands.

What is proposed is a people-centred approach to healthcare, combining health

as a social activity with the building of networks of trust. This is significantly different from self-care models, which result in self-monitoring and self-diagnosis products for solitary use.

The central feature of the Circles of Care model and health as a social activity, is the network. The network is key and is, in effect, the product of the service. At the moment, healthcare systems are improving the delivery of solutions to problems, but this new model provides a "support space" before the problems arise and the capacity to respond when they do.

### Who will play a role?

The Circles of Care model is based on existing networks around which new services can encourage us to build, share, adapt and pass on to others knowledge, experience, support and concern. Who will play a role in providing platforms to enable these?

### Technology

To discuss the role technology can play in supporting health networks we can take two future scenarios of the development of technology, classified by sociologist James Robertson.

One model takes technology as a solution for everything – *technology as master.* In this future, medical technology will solve most health problems, but it will increase the dependence on medical experts and technologists. There are several digital health services, that follow this approach. For example, many self-care projects which use sensors to collect your biomedical data treat health as pure data and often only deliver stockmarket like charts of information which ignore the social and cultural dimension of your health.

Another scenario takes the use of *technology as a servant*. This foresees that greater responsibility for health will lead people to the proactive cultivation of their health and to the positive promotion of a healthy physical and social

environment. In this model, personal selfhelp and cooperative mutual aid in matters of health and sickness will be more highly rated than dependence on the expertise of health professionals.

To date, far less work has been done on treating health as a social experience – starting from the bottom up with experiences and social context – than on technologies and digitized data. This is a significant gap, but also an opportunity to explore the potential benefits of new and emerging technologies.

### Stakeholders

In this model, the 'conscious well' play the role of the active health consumer. They are the people who are concerned with and aware of their health on a daily basis. These health consumers will be more proactive, more informed and more demanding about products and services for daily well-being. They will be more networked to their partner, relatives, friends and local area, and will actively seek well-being and healthy life styles.

Today, people spend a significant amount of money on what they see as health support, such as vitamins. Such people will also be motivated to invest when they realise that health lies in Circles of Care. The market of healthy people who want to be more healthy is much larger than the market of healthy people who fall ill.

## < The designer will play the role of the mediator between the 'conscious well' and the service providers. >

"By 2000, it was estimated that Americans who use alternative health care spend about \$500 out of pocket annually. The market for nutritional supplements was estimated at between \$92 billion and \$200 billion. Small wonder that 70 per cent of consumers told pollsters that availability of alternative care was a top criterion in their choice health plan." (Zuboff S, 2003)

*Communication technology* companies play the role of the well-being service providers in this model. Apart from business networks and personal communications, these companies will provide platforms for health and well-being, creating new networks around our Circles of Care. They will be closer to their customer because they meet social needs. These companies will also include in their brands the idea of being 'health conscious'.

**Product retailers** from food to clothing already address the self-care health consumer. They will answer to the growing market of the Circles of Care demand. This network of health is the new customer. The important factor for such retailers is that they can think of consumers as growing peer groups with whom they can develop lasting relations. Consumer feed back can be very direct, leading to product improvement, support and extentions that increase loyalty. This defines new ways of thinking about brands, that have a wider emotional and social value than individual products can deliver. *Medical product companies* can incorporate the Circles of Care concept into their product strategy to reach a wider market. The service around the product adds to its social value and can be a critical success factor in the global market. Similar factors to those affecting retailers apply here and the potential for closer relations between producer, retailer and consumer offers opportunities for new markets, supported by communication and information technologies.

**Designers** will play the role of mediators between the 'conscious well' and service providers. Involved right at the beginning of any new product strategy, the designer's task will be to envisage services and associated products that can respond and adapt to changing user needs and life stages.

*Voluntary sector organisations* are already close to people and can, in partnership with network providers, become enablers of services by bringing expertise and the important 'trust factor' to the consumer. They will benefit from the opportunity to reach out to larger numbers of people in more effective ways.

*The public sector* will not find itself in competition with the networked-centred health system, but will be able to concentrate on delivering highly specialist medical services while benefiting from the opportunity of working in close relation with very local community based networks.

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## SERVICE narratives



Service narratives Servic



Four ongoing case studies and eight service narratives are explained in the following pages to illustrate how communication and networked technologies can provide platforms for social networks of health. These services aim to encourage proactive health routines.

### **Case studies:**

*PatchltUp* allergy monitoring patches by Pearson Matthews show how a self-monitoring device and mobile communication can incorporate Circles of Care. It is a wearable allergy sensor for children that alerts the child and its circle of care member if an allergic reaction is occuring.

*Sweet Talk* by Orange is an example of using sms technology and peering to motivate and monitor daily health routines amongst a group of diabetic children.The children and the doctor are part of an sms network which enables them to send daily support messages and allows them to ask questions via sms.

*Eye coach* by Gero Grundmann, Helen Hamlyn Research Associate 2004 with Guide Dogs for the Blind Association is an example of the voluntary and private sector teaming up to provide a proactive health service based on people's existing network of care. The Guide Dogs charity provides active learning cards for gym instructors, so that they can encourage gym visitors to < The service narratives are presented as</p>
Inspirational scenarios for service companies, designers and consumers. >

take care of both their body and their eye sight.

*Change to Prevent* by Teko design consultancy for Bayreuth Breast Cancer in Germany is an example of a clothes retailer and a medical expert providing a proactive breast cancer prevention service in changing rooms. This takes an existing point in a social network of care to encourage health monitoring. The project uses changing rooms, where women already discuss their emotional and physical health, to remind them to test each other for early signs of breast cancer.

### **Service narratives**

The following pages introduce eight service narratives that respond to a network of care. These services and products are scenarios that set up a situation where Circles of Care meet a service. They are based on personal stories of individuals who experience a change in their circle of care (displacement, moving, loss of partner).

Each service is illustrated at a moment where it is experienced by the user. For example, when using it, when receiving a letter from the service provider or when joining. Lets take the service of a bank account as an example: most of the time it is in the background and we experience it when we take out money or when we receive our statement telling us how much interest we have made, or have not made. These points of contact with the service are where its value shows, unlike products where the value lies often in possession not use. At present the service economy is a culture of use rather than a culture of possession.

The service narratives address the health activities previously defined with the different activators of the Circles of Care, like partnering, friends coaching, or neighbourhood health. The narratives evolve around main life events that have a strong impact on building, adapting, sharing or passing on circles of care.

These narratives are presented as inspirational scenarios for service companies, designers and consumers to contextualise how Circles of Care services can be designed.

o

Call mum for free <sup>©</sup>

William Brooks has moved to another city to start a degree in electronics at the university. It is the first time he has lived away from his hometown. He will learn a lot of about resistors and transistors. He will learn how to take care of himself too.

call mum for free

Orange Suppliere Inte 19 win pool o your

ery monday your mum is liting for your phone call

Will got a letter.

40°41

Post of the owner of the second second of the second of th and the second second second CIRCLE OF CARE STAGE Build a circle of care for the first time ACTIVATORS His family: he still depends on his family's circles of care SERVICE DESCRIPTION Free call to your mum for 15 minutes, every Monday for one year Enhance communication between William and his family CONSUMER BENEFIT Calling mum for free SERVICE PROVIDER BENEFIT Get closer to the consumer's personal network Augment the frequency of customer communication TYPE UP SUMPLY Source of voice recognition database to identify changes in user wellness LONG TERM STRATEGY Introduce the 'health conscious' brand to a wider audience

CALMMER FREE BOLDIN TO CICLOS OF CASE

Des M Brook

# Health heritage blog ©

Bernard has been offered a job abroad. His younger sister is already studying in another city. Bernard thinks it is good to work away from his hometown for a while but his girlfriend is waiting for him to come back. Bernard and his sister want to collect the knowledge from their parents self-care strategies (cooking recipes, home remedies, first illness symptoms). This knowledge will activate their self-care routines even though they are miles away from home. They don't know how to collect this family data.

Bernard and his sister have a solution.

# My Health Heritage BLC

Home remedies, cooking tips, healthy routines, and sport advice... everything about my family HERITAGE. Sponsored by CIRCLES OF CARE® by

# Saturday, September 04, 2004

bernard, this islice event sisters healthy tip

 CIRCLE OF CARE STAGE
 Discover and document his family's health heritage

 ACTIVATORS
 His sister: she is in the same situation

 SERVICE DESCRIPTION
 Blog space to collect strategies of health and well-being of a family

 CONSUMER BENEFIT
 Learn how to build his circles of care to stay healthy

 Closer involvement with the consumer and his/her family

 TYPE OF COMPANY
 Health and well-being product retailer

 FUTURE POSSIBILITIES
 Create a database with the customer's health routines

 LONG TERM STRATEGY
 Offer 'life-long' services, encourage customer loyalty

Abo

# Dad sent a mob-card ©

Julian Moore is 38, married and has two young daughters, Sara and Isabel. He travels to Switzerland once a month on business. He used to enjoy a good fondue as well, but Julian has high .cholesterol and now he can't eat very fatty meals. He knows that. His daughters know it too.

Family Contrad

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alot tamer setting u a pc from with setting u a pc from undt with from training undt with i from as you con see from as you con see from as you well i from a u to set of the as you con see

His family got postcards from him.

**42**°43

ACTIVATOR SERVICE DESCRIPTION CONSUMER BENEFIT SERVICE PROVIDER BENEFIT TYPE OF COMPANY	NT Work abroad E Share his circles of care with his daughters S His daughters: they monitor what he eats J Julian can send a postcard home with a picture taken by his mobile His daughters have a platform to monitor his health when he is away Incentive to keep a healthy routine when travelling Increase contact with his daughters Close identification with the consumer's personal network Build an emotional relationship through a network Communication company Create 'warmer' technologies for a specific context of communication
	s specific context of communication



John and Margaret have lived together for a very long time. John is 67 and retired from the railway company two years ago. He has high blood pressure and has to take care with salty meals. Margaret was a housewife. She always monitored John's meals putting, less salt into the cooking. Last year Margaret died of colon cancer. There is no one to monitor John's salt intake.

John got a present from his niece.

 LIFE EVENT
 Loss of a circle of care

 CIRCLE OF CARE STAGE
 Rebuild a circle of care

 ACTIVATORS
 His family

 SERVICE DESCRIPTION
 Personalised objects that resonate circles of care from the past

 CONSUMER BENEFIT
 Objects to help him remember healthy routines

 SERVICE PROVIDER BENEFIT
 Reach a new market that merges personal experiences with objects

 TYPE OF COMPANY
 Product designer, retail

 LONG TERM STRATEGY
 Expand product range

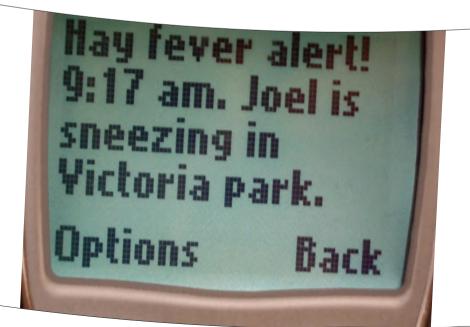


Hay Fever peer alarms ©

Claire, Mark, Susan and Joel work in the same insurance company in the West End. They are in different departments but usually meet in the canteen. They are in their mid thirties and like to talk about how they feel. They usually exchange healthy tips during lunchtime. They all suffer from hay fever.

Joel sends an alert on his way to work.

TYPE OF LIFE EVEN	
TYPE OF LIFE EVENT Always at work	
ACTIVATORS Work	
Schvice Description	
Volem the	
ACTIVATORS Work colleagues SERVICE DESCRIPTION System that enables to send sms alerts to work colleagues when the first symptoms arise CONSUMER BENEFIT 'Real time' location-based awareness of allergy risk SERVICE PROVIDER BENEFIT Create networks based	
BENEFIT 'Real times'	
SERVICE PROVIDER BENEFIT Service PROVIDER BENEFIT Service PROVIDER BENEFIT Create networks based on health conditions TYPE OF COMPANY LONG TERM STRATEGY P.	
THE PROVIDER BENEFIT Concerned to the second awareness of all	
oreate networks be	
Type on heach and have a set on boots and control and	
LONG TEPM and Mobile Come	
STRATEGY Be percent	
Porceived as 'communication	
supporting t	
LONG TERM STRATEGY Be perceived as 'community' supporting brand	



# Count on us too ©

Peter is 69, retired and very opinionated. For example, he always complains about the health service in his country. He thinks that is doesn't work. He thinks that the government is waiting, for him to get ill to do something, but in the meantime they don't care about how he takes care of himself.

Peter smokes a lot and today smiled about the pack of cigarettes.

Your friends

and family

can help you stop

smoking

TYPE OF LIFE EVENT CIRCLE OF CARE STAGE ACTIVATORS SERVICE DESCRIPTION CONSUMER BENEFIT HEALTH SYSTEM BENEFIT

> TYPE OF COMPANY LONG TERM STRATEGY

Retirement Needs a circle of care to quit smoking Family or friends Tobacco warnings that address family and friends as main activators Catalyst to ask for help from family and friends Healthier and more responsible population Consumers refer to family and friends for personal health matters Health system (NHS) Long term education, reduce strain on health systems

# Who gained weight ?°

Today Sarah and Tim weighed themselves on their bathroom scales together. It shows half a pound more since the last time. It was him who gained weight? Or it was her? Or both?

Today they were very quiet at breakfast.

46°47

LIFE EVENTLive togetherCIRCLE OF CARE STAGEShare circles of careACTIVATORSPartners, motivating each otherPRODUCT DESCRIPTIONBathroom scale that encourages controlling weight togetherCONSUMER BENEFITMotivate and monitor each otherCOMPANY BENEFITExpand product rangeTYPE OF COMPANYProduct manufacturers, retailLONG TERM STRATEGYCreate products with a social and well-being function

# My healthy postcode ©

Alice sometimes has low immune levels. She does blood analysis regularly and she has to control what she eats. She also wants to be healthy for next summer because her best friend is getting married and she wants to look great. She read on the internet that zinc is good for the immune system. She is too lazy to check which products contain zinc.

Her supermarket will check for her.

CUSTOMISED BILL FOR ALICE WHITECHAPEL £0.79 £1.64 ZINC++ Age Over 18 ORGAN WHL MILK \* PINK/GFRT DRNK Cashier Confirmed -\* MARQ DE GRINON CUCUMBER PRTN DEANS LRG EGGS BGTY TRIPLE CHOC 2THC. MISC CHPD TOM MORINAGA TOFU £0.96/ Kg TIGDO 091 Kg

TYPE OF LIFE EVENT	Temporary condition (immune system low)
CIRCLE OF CARE STAGE	
ACTIVATORS SERVICE DESCRIPTION CONSUMER BENEFIT SERVICE PROVIDER BENEFIT TYPE OF COMPANY	Her neighbourhood Personalised supermarket bill that indicates amount of specific food components Extra information helps her to control her zinc intake Closer understanding of the customer needs and health problems

conclusion: where next?

**48°**4

Conclusion Conclusion

This report has introduced a new concept called Circles of Care which describes an approach to healthcare based on social networks.

In looking at how people maintain their health, the study has identified an 'inbetween' space between self help and the expert help of medical professionals that has potential for development.

This area has been identified using design ethnographic research techniques to investigate displaced people moving to a new town or country, who have been forced by necessity to construct a new circle of care.

A map of the inbetween space has been created showing how Circles of Care support people at different life stage. A suite of service narratives have been developed to illustrate the concept and generate a debate on how the map could be populated with new services in the future.

As the project took shape, the driving question became: what kind of Circles of Care can be identified and evolved, and what new services are needed to sustain them?

Now at the conclusion of the study and the establishment of its central proposition, it is important to mark a new beginning. The next steps following the publication of this report should be to forge new partnerships and populate the inbetween space through case studies and realised design proposals. In this way, Circles of Care will ease pressure on existing medical services, achieve social inclusion aims and offer business opportunities.

### **Bibliography** Arnold K (2003) Medicine Man, British Museum Bettie A, Gott M (1993) Health & Well-being: a Reader, The Open University Boon T, Jones I (2003) Treat yourself, Science Museum Boon T. Lawrence T (1994) Health Matters. Science Museum Brown J S, Duguid P (2002) The Social Life of Information, Harvard Business School Department of Health (2003) Design for Patient Safety, Design Council Diener E, Suh E M (2000) Culture and Subjective Well-being, MIT Press Engel C (2002) Wild Health, Phoenix Laurel B (2003) Design Research, MIT Press Powazeck D M (2002) Design for Community, New Riders Robertson J, (1998) Beyond The Dependency Culture Rojek C (1997) Touring Cultures, Routledge Sontag S (1978) Illness as Metaphor Zuboff S, Maxim J (2002) The support Economy, Penguin Press

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A new approach to healthcare based on social networks

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The Helen Hamlyn Research Centre Interaction Design, Royal College of Art Research partners: Pearson Matthews and Orange

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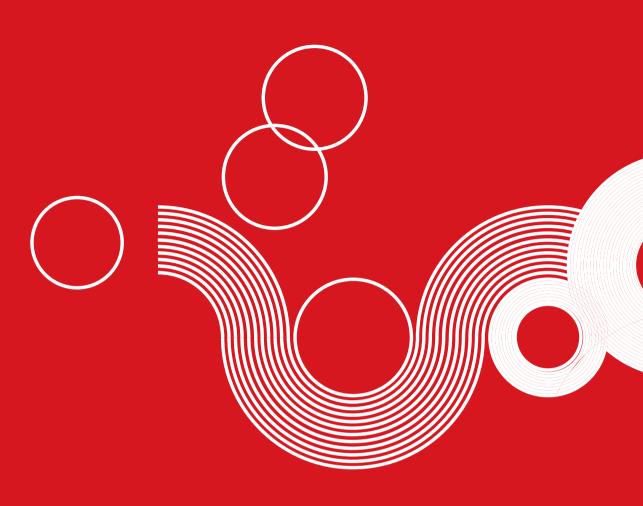
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www.circlesofcarebook.com



The crisis of healthcare systems is an ongoing issue, especially in European welfare states. In the UK we currently have a system where we wait for people to get ill before we treat them. The ideal patient follows the expert's instructions without dispute. This is similar to a child's health being the full responsibility of its parents.

However, people are now becoming more responsible for maintaining and monitoring their own bodies. Hence the growing movement towards self-care and personal well-being. Increasingly we look to social networks of support before going to the traditional expert system. But these social networks – the Circles of Care – currently receive little attention from design and industry.