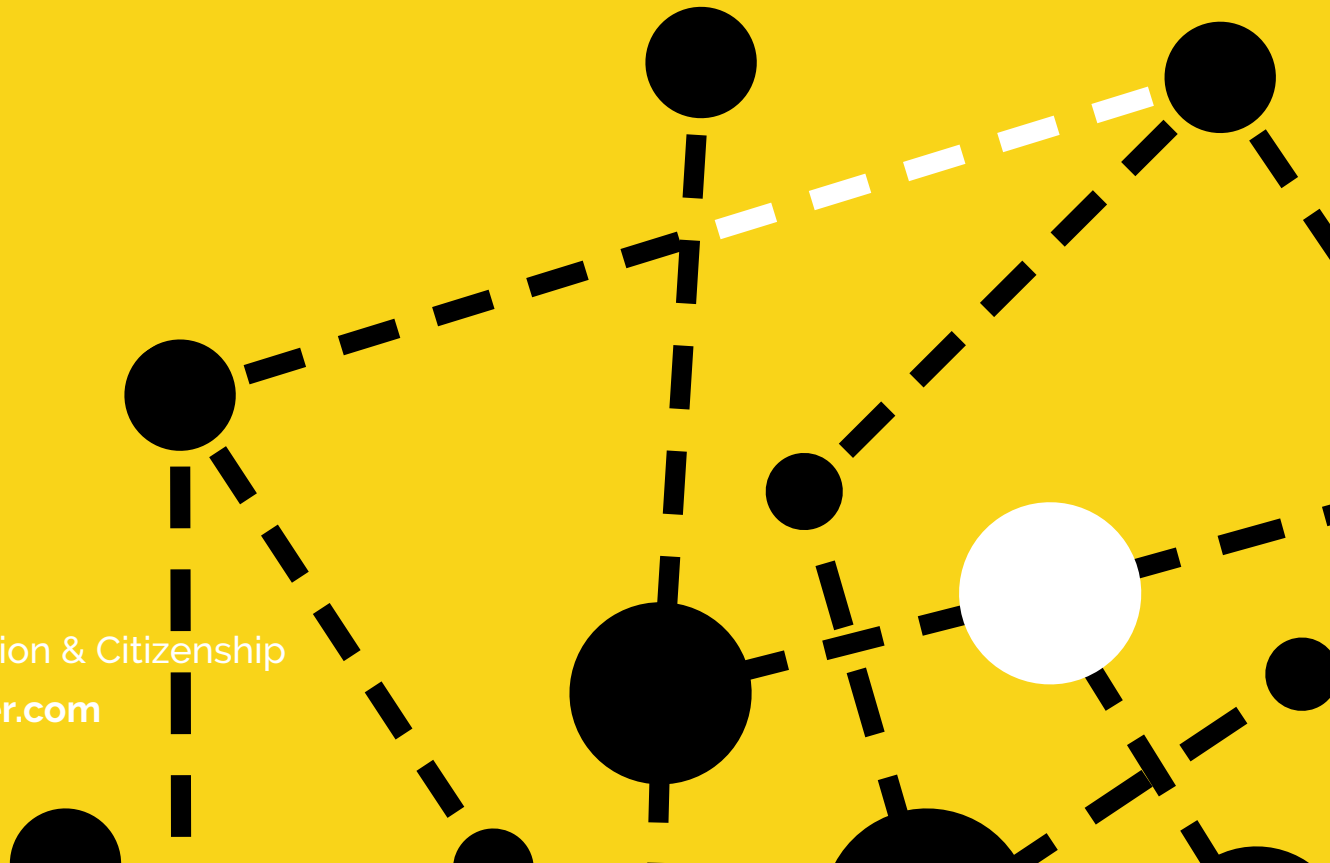**UTE SCHAUBERGER**

Salty Lives

Unravelling Healthcare Through the Lens of Living with Cystic Fibrosis

Ute Schauberger

Design Innovation and Citizenship
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www.uteschauberger.com

Salty Lives

Unravelling Healthcare Through the Lens of Living with Cystic Fibrosis

Salty Lives is a design experiment into how design-led approaches might begin to unravel, interrogate, and re-envision healthcare by exploring it through the lens of living with cystic fibrosis.

By investigating this specific context, its barriers, and opportunities, it aspires to also interrogate the organisational structures, services, and systems around healthcare more generally. It uses design research to critically examine emerging patterns of living, to address and explore the questions they throw up, and to uncover and articulate alternative trajectories. Salty Lives is an inquiry into how we might live with chronic illness, but also into how we might design. It explores how design practices can be applied to reimagine the cultures, institutions and systems that shape our world.

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Here I include references to other people's work that shaped this project, as well as some of the data I collected during my own research in more detail.

Introduction

SALTY

/slti,s-/

1.
tasting of, containing, or preserved with salt.
"the bacon will be quite salty"
synonyms: salt, salted, saline, briny, brackish

2.
(of language or humour) down-to-earth; coarse.
"her wild ways and salty language shocked the local gentry"
"the Princess has a salty sense of humour"
**synonyms: lively, vigorous, spirited, colourful, sparkling, zesty, zestful,
spicy, sharp, racy, piquant, pungent, tangy, biting, informal, punchy**

(Oxford Dictionary)

Cystic Fibrosis

People with CF have more chloride (salt) in their sweat than someone who does not have CF. Therefore their skin tastes extremely salty. So do their kisses. And their tears.

Cystic fibrosis (CF) is one of the UK's most common incurable chronic conditions caused by a single faulty gene that controls the movement of salt and water in and out of cells. CF slowly destroys all internal organs as they become clogged with thick sticky mucus. This results in chronic infections and inflammation in the lungs, difficulty digesting food, as well as a range of other challenging and life-limiting symptoms.

I have lived with CF for 26 years. It's been wonderful, if a little breathless.

PART 1

A Journey Through Design

Here I discuss and reflect on my role and where I started, how this project has transformed my design practice, the methodology and methods I applied, and the ethical considerations involved.

Where I Started

A Salty Life

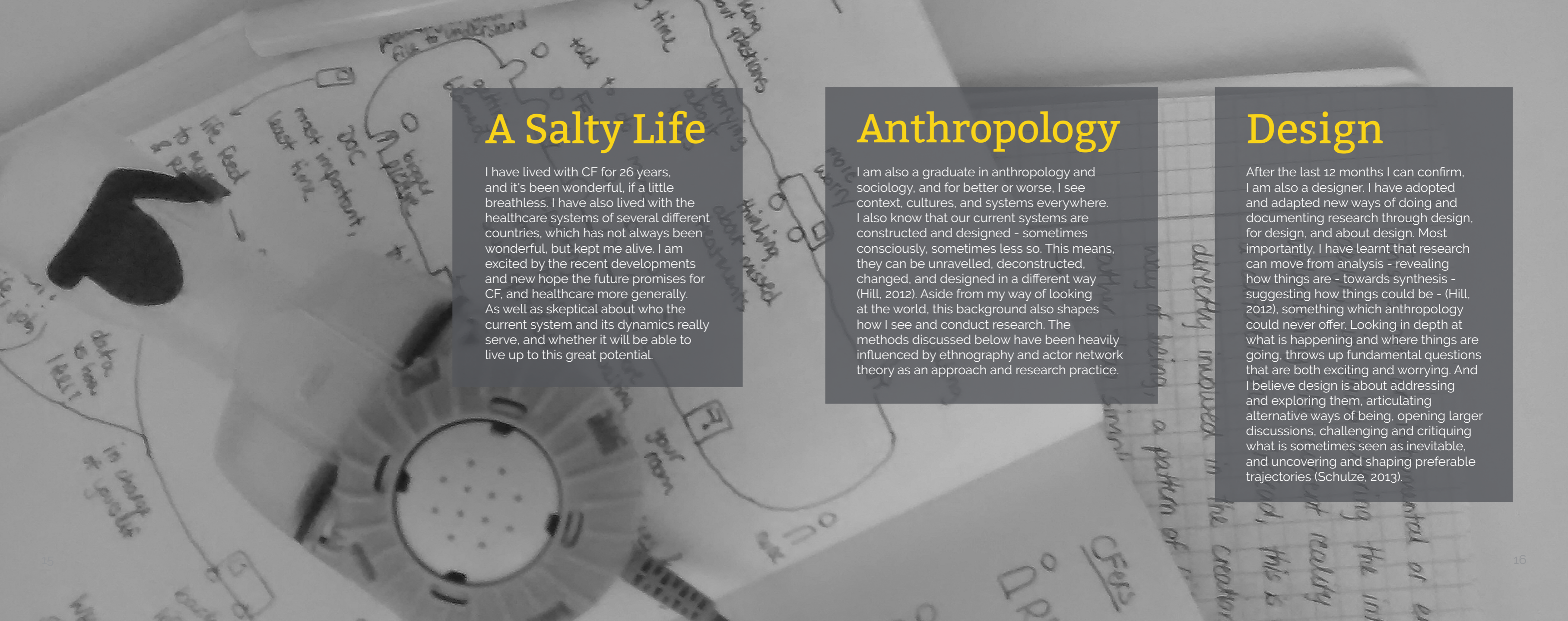I have lived with CF for 26 years, and it's been wonderful, if a little breathless. I have also lived with the healthcare systems of several different countries, which has not always been wonderful, but kept me alive. I am excited by the recent developments and new hope the future promises for CF, and healthcare more generally. As well as skeptical about who the current system and its dynamics really serve, and whether it will be able to live up to this great potential.

Anthropology

I am also a graduate in anthropology and sociology, and for better or worse, I see context, cultures, and systems everywhere. I also know that our current systems are constructed and designed - sometimes consciously, sometimes less so. This means, they can be unravelled, deconstructed, changed, and designed in a different way (Hill, 2012). Aside from my way of looking at the world, this background also shapes how I see and conduct research. The methods discussed below have been heavily influenced by ethnography and actor network theory as an approach and research practice.

Design

After the last 12 months I can confirm, I am also a designer. I have adopted and adapted new ways of doing and documenting research through design, for design, and about design. Most importantly, I have learnt that research can move from analysis - revealing how things are - towards synthesis - suggesting how things could be - (Hill, 2012), something which anthropology could never offer. Looking in depth at what is happening and where things are going, throws up fundamental questions that are both exciting and worrying. And I believe design is about addressing and exploring them, articulating alternative ways of being, opening larger discussions, challenging and critiquing what is sometimes seen as inevitable, and uncovering and shaping preferable trajectories (Schulze, 2013).

Design

Design Practice and Approach

This project has been a conversation with design, citizenship, anthropology, and living with CF. As a result how I define and understand 'design' has shifted and changed throughout these weeks. My thinking and doing has been shaped by work that is easiest to summarise as strategic design. And sometimes it was easy to locate these concepts, theories, and frameworks within my practice, other times my experience of applying them was very different or had limited success.

Designing for citizenship means considering the broader application of design practices for society and its organisational structures, services, and systems. They make up our social contracts, or the conditions in which society and culture unfold, and I would argue that they can be changed and redesigned at both the individual and institutional level. With this project, I looked at healthcare, but worked with a specific disease as 'an area of inquiry, allowing for investigations into specific contexts, barriers, and opportunities, which then inform the development of more generalised, systemic improvements' (Boyer et al, 2013:9). However, it often proved difficult to keep track of both these levels - to reflect meaningfully on the impact of one on the other, and to potentially iterate accordingly - while still in the middle of the research process. Designing research methods that themselves produce insights which zoom in and out of the individual and institutional level helped me to achieve this better, but it was much more difficult to also implement this when working on my design response.

Still, I see all design as directly involved in creating culture, ways of being, and patterns of living. And I see no reason to not use design practices consciously and purposefully towards articulating certain values or formulating a vision. What Hill (2012) calls strategic design, then has 'a direction, over and above being a set of tools, a vocabulary, and a series of projects'. For strategic design, a new form of design challenge is the 'vital, messy reality of taking a vision, transforming this into a strategy and then making it happen' (Hill, 2012). Within my project I found it particularly challenging to transform vision into a concrete prototype that is easy to understand, can be tested, and iterated. It was difficult to decide how to communicate the larger vision within a concept, to narrow down what I need to know to move forward, how to test my ideas within my limited access and time-frame, and how to decide on their success or failure. I agree with Boyer et al (2011:113) that when working in this space, the challenges are 'as much about vision as they are about designing the transition to accomplish that vision.'

A way forward lies in a different and more investigative conception of design itself, 'one not overly focused on problem solving, or pretending to embark towards a resolution with a clear idea of the answer' but based on prototyping and iterating. It is about interrogating affordances and making small moves that might shift the pattern at the macro level even when it is impossible to understand the whole system fully (Hill, 2012:). Design research is then a practice where 'observing is intrinsically tied to designing. Without the designing happening there can be no meaningful observation.' (Blythe, 2010). Analysing and presenting data is followed by synthesis and resolving into a course of action. And in fact, the overall challenge might not be to create either visions or transitions through design methods, but to produce systems that make this approach possible and that can learn from failure.

The Design Outcome

My approach to arriving at a design response for this project was then to fold my insights into a proposal (Boyer et al, 2013:31). Still, the outcome is not a preconceived solution, but an improvisation from which one might learn a course of action (Boyer et al, 2011). Prototyping in this sense assumes that 'what we make today does not have to be the limit of what we hope to accomplish tomorrow' (Boyer et al, 2013:18). And my design response should be read as an assertion that the idea of design can be extended to suggest that 'the making of things can also affect the formation and function of the more diffuse layers around it: the cultures, institutions, and systems that shape our world.' (Boyer et al, 2013:18)

Methodology and Methods

Methodology

My approach to exploring healthcare as a system through the lens of living with CF consisted of a series of activities iterating between zooming in and out of this network, its actors, and their relations. Throughout, I mapped and documented the resulting findings and insights, and aimed to explore emerging trends and behaviours. The design outcome is a response to some of the issues and directions this process revealed, but is also intended to ask further questions and provoke reflection.

Methods

Visual Mapping

First, I identified the main actors within CF care based on personal experience and knowledge, and started mapping their relationships and motivations. I checked this against information from the CF Trust and NHS, and added to it throughout the project. This approach is loosely based on actor network theory as a research method (Latour, 2005). Taking people with CF as starting point, I explored and began to unravel some of the network and relations that make up healthcare today.

Expert Interviews

Next, I spoke to as many actors within this system as possible, to explore diverse angles on healthcare. During these interviews I tried to focus the conversation on the bigger picture, the future of this system, and where opportunities lie. However, this approach did not prove particularly successful, many people had simply never considered these questions and even when leading with a proposal as I tried later (Boyer et al, 2013:30), they found it difficult to give an opinion on the spot from what they saw as their isolated position. Instead, I changed my approach and focused on their own work right now, and on testing and revising some of my assumptions about their perspective and contribution.

Literature and Case Studies

I was particularly interested in the social innovation this network has experienced alongside technological changes, e.g. in how knowledge is created, negotiated, and diffused between different actors. I agree with Boyer et al (2013:9) that new ideas 'may be conceived of in the abstract but ultimately must be built amidst and within the old'. Thus I aimed to develop a grounded understanding of where this system and its actors might be headed in the future, and looked at existing literature and case studies, after expert interviews could not really answer this. I looked at emerging behaviour and trends, but also at case studies where these conversations had been driven forward more concretely, within and beyond healthcare, and where the traditional one-dimensional view of how to address disability and chronic illness had been challenged.

Ethnography

Through ethnography, I aimed to explore how people with CF relate to this complex system of healthcare and its future more specifically. In this sense 'exploring' meant to observe, listen and experience a social setting and relations through participant observation which can provide 'rich, rounded, local and specific' data for analysing one particular case (Mason, 2002:89). It allowed me to look at a range of dimensions including the physical settings and non-human actors within this network (Mason, 2002:85; May, 2011:178). It also provided an opportunity to study interaction as it occurs in specific contexts rather than reported or constructed within retrospective accounts (Mason, 2002:85).

Digital Ethnography

On the other hand, in all networks people are already 'busy interpreting and understanding their environments' (May, 2011:170), and to find out more about their perspective, I started exploring the online world of the CF community. Every week, I read one blog by someone with CF in detail. I also looked at the bloggers' Twitter and Facebook feeds, and paid close attention to reoccurring issues around life with CF. As CF patients cannot meet each other, this online space has thrived in recent years. It is a digital public space where I could observe as well as participate in how people construct their identity as someone with CF, how they see and describe themselves as an actor within the healthcare system, and how these roles can be in conflict and characterised by control and resistance.

My Role

The resulting analysis is of course not a 'full and neutral account of a setting or set of interactions' but selectivity and perspective inadvertently play a role for these findings (Mason, 2002:89). As my research is not and cannot be independent from my own biography, this project should be read with an awareness of my own context and connection to CF. Of course there are tensions associated with this, and how I interpret findings is affected by my double roles as design researcher and person with CF. Everyone I spoke to during these weeks was informed that I live with CF, and thus made their own conclusions on where I stand relating to the healthcare system, which of course shaped our interactions. I have been both observer and participant for a long time when it comes to CF care, and even when I reflected on my interactions with healthcare more in-depth during these 12 weeks specifically, clearly much of my more long-term experience has fed into this project. Being accustomed to CF and its care helped me gain deeper understanding as I could draw on this experience to comprehend actions in context (Coffey, 2002). My experience of this setting is consequently itself a reconstruction and I cannot assume that it matches that of other actors. To avoid misrepresentation, I have however complemented ethnographic research with methods focusing more on the experience of others as described above (May, 2011:136). I am part of the world I aim to understand and design for, but this is 'not a matter of methodological commitment, it is an existential fact' as the presence of a researcher will always affect the research (Hammersley and Atkinson, 1995:15). Already being part of the scene and accepted to some degree could in fact be argued to keep this effect at a minimum and had other advantages as it was easier to get access to and build rapport to certain participants.

Ethics

31

32

My own connection with CF also helped me when approaching sensitive topics and conducting research ethically. I know the risks of cross-infection and only engaged others with CF online rather than in person, I knew it was important to be flexible with time and research methods as people might be experiencing ill health, and I had an idea of what not to ask, where to stop, and when to take breaks. I am also aware of some of the complexities around ways of portraying people with CF, thus ethical considerations have not only been built into my research process but also into delivering its results. This helped not only to protect participants, but also myself.

I felt it was important to only contact people with CF who are very public about this online, who act as patient advocates, and activists. I engaged them because of their connection to CF rather than as 'patients' within the NHS. This helped to avoid some of the problems related to revealing identities and attitudes, and using private information or patient data, but it also enabled this project to explore a much deeper and wider picture of health and illness.

Wherever possible, I asked participants about any other concerns they might have regarding ethics and privacy, and informed them that they can stop the conversation at any point, not answer questions, and change their mind later about how our conversation will be used. I also aimed for transparency by keeping people updated and asking for consent to how their stories are used with progress and outcomes before publishing this book. This was also important to some of the experts who work at different and potentially opposing ends of the healthcare system.

Still, informed consent is not a straight forward issue when it comes to digital ethnography. Websites, blogs, and forums can be considered public digital spaces, and being seen and heard as someone with CF is part of the agenda of many activist patients, and they implicitly encourage to share their stories. Yet explicit consent from every single person involved was often not possible and data from digital ethnography has therefore been anonymised within this book.

In my experience, it can be empowering to be asked about living with CF, to reflect on this experience, and to imagine preferable futures. Throughout this project, I tried to give opportunities to do so as a way of giving back to the CF community and participants.

PART 2

A Journey Through Healthcare

Here I illustrate my journey through the world of cystic fibrosis and healthcare, I talk about the context, findings and insights of this project, and describe how I got from issue to opportunity and design response.

Cystic Fibrosis

What causes CF

FATHER

One copy of the
faulty CFTR gene

CF carrier

MOTHER

One copy of the
faulty CFTR gene

CF carrier

CF is an inherited disease
and more than 2.5 million
people in the UK carry the
faulty gene, around one
in 25 of us – most without
knowing. Each week five
babies are born with cystic
fibrosis, and there are
around 10,500 people living
with CF in the UK.

CHILD

Two copies of
normal CFTR gene

Does not have CF

CHILD

One copy of the
faulty CFTR gene

CF carrier

CHILD

One copy of the
faulty CFTR gene

CF carrier

CHILD

Two copies of the
faulty CFTR gene

Has CF

The abnormal gene causes the protein controlling the movement of salt
and water to not work properly. It retains salt, which leads to thick and sticky
mucus plugs throughout the body.

Normal airway

thin layer of mucus

airway wall

outside cell

inside cell

chloride ions

Airway with cystic fibrosis

thick layer of mucus

mucus

*(All medical information, statistics, and medical diagrams about cystic fibrosis and its biology have come from the UK CF Trust
website and publications available at http://www.cysticfibrosis.org.uk)*

Symptoms

This thick mucus plugs up the lung, pancreas, and sinus. It causes malnutrition, frequent pneumonias and inflammation in the lung, liver disease, diabetes, and low bone density. Eventually CF leads to respiratory failure and death as the airways collapse or the damaged and inflamed lungs become overly stretched. At the moment, CF is treatable but not curable. Around half of the CF population in the UK will live past 41, and this is a huge improvement from a median survival age of around 20 years as recently as the 1980s. Still, every week two people in the UK die of CF, and half those are aged 28 or younger.

Lungs

Frequent productive coughing, shortness of breath, infections, inflammation, bouts of bronchitis and pneumonia

Pancreas

Inability to digest food and malabsorption of nutrients and vitamins, diabetes, ongoing diarrhea and stomach pain, dehydration and malnutrition despite huge appetite

Skin

Abnormally salty sweat and salty tears, finger clubbing

Sinuses

Chronic infection and pain, nasal polyps, equilibrium problems

Intestines

Blockage and constipation

Bones

Low bone density, osteoporosis, arthritis

Liver

Liver damage

What this means

What this means for most people with CF is coughing almost constantly, bringing up sticky and at times bloody mucus, being exhausted quickly, being in pain, having frequent infections and pneumonia, and dealing with indigestion. Many people with CF describe how they feel as 'drowning from the inside.' It also means worrying about declining health, the future or an early death, and managing other people's worries and fears.

It means taking over 30 pills, doing several hours of boring and painful physiotherapy, doing regular exercise, maintaining a high fat diet, and fitting in life in between - every day. Some days, it means lengthy hospital check ups, long hospital stays, pharmacy visits, frustrating test results, esxplaining your condition to others who might dismiss it, conflicts and misunderstandings with doctors, missing school or work days, tube feeding, IV drips, oxygen machines, pain and exhaustion, various side effects, forgotten treatments and feelings of guilt.

Neither of these is an exhaustive list of complications. And both leave out the good parts of life with CF. For example the excitement of your best friends kidnapping you and your oxygen machine from hospital to go to the cinema. Or feeling strong and free like a superhero walking by the sea where the salty air makes breathing easy. Or the sweetness of your first kiss after a period of not being able to kiss for lack of breath.

Treatment

Treatment of CF consists mainly of methods to remove and thin mucus and medications to treat digestive problems and infections.

Recently, a new type of treatment has given people with CF hope. The precision medicine Orkambi for the first time tackles the underlying cause of cystic fibrosis - the genetic defect - rather than just its symptoms. However, it is very expensive, and its long-term value and impact are still unsure. So far the NHS has rejected to take on the costs of Orkambi.

Physiotherapy
breathing exercises to cough up mucus

PEP and Flutter
breathing through them creates pressure and vibrations in lungs to loosen mucus

Vitamin and Nutrition Supplements

The Vest
vibrates to loosen mucus

Lung Transplant
when otherwise reaching end of life

Nebulisers
inhaling medication that helps break up mucus or fight bacteria

Antibiotics and Steroids
oral or IV, to fight bacterial infections and inflammation

High Fat Diet
to maintain weight

Tube Feeding
when absorbing too few nutrients from food

Long-term Oxygen Therapy
when blood oxygen levels dangerously low

Healthcare

The Healthcare System

feel better, find a cure, live well

PATIENTS

ambiguous position and interest, many stakeholders

speak out

PATIENT ORGANISATIONS

collaborate

treat, heal, prolong life

NHS

treats

exchange data

appeals to

funds

lower cost and increase efficiency of healthcare

collaborate

sells drugs to

approves drugs

GOVERNMENT

NICE - National Institute for Health and Care Excellence

achieve value for money, guarantee safety, make ethically and financially viable decisions

PHARMA INDUSTRY

sell products, make profit

mindsets
expectations
data
knowledge
ownership
ethical value
monetary value
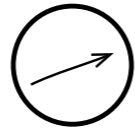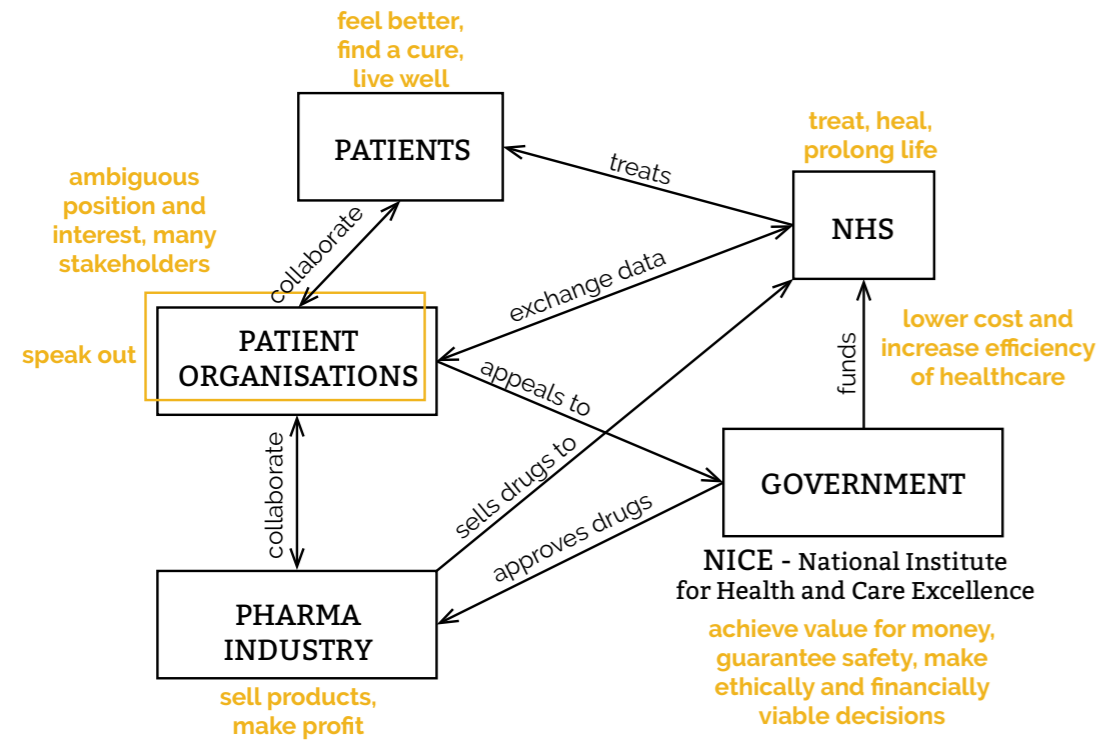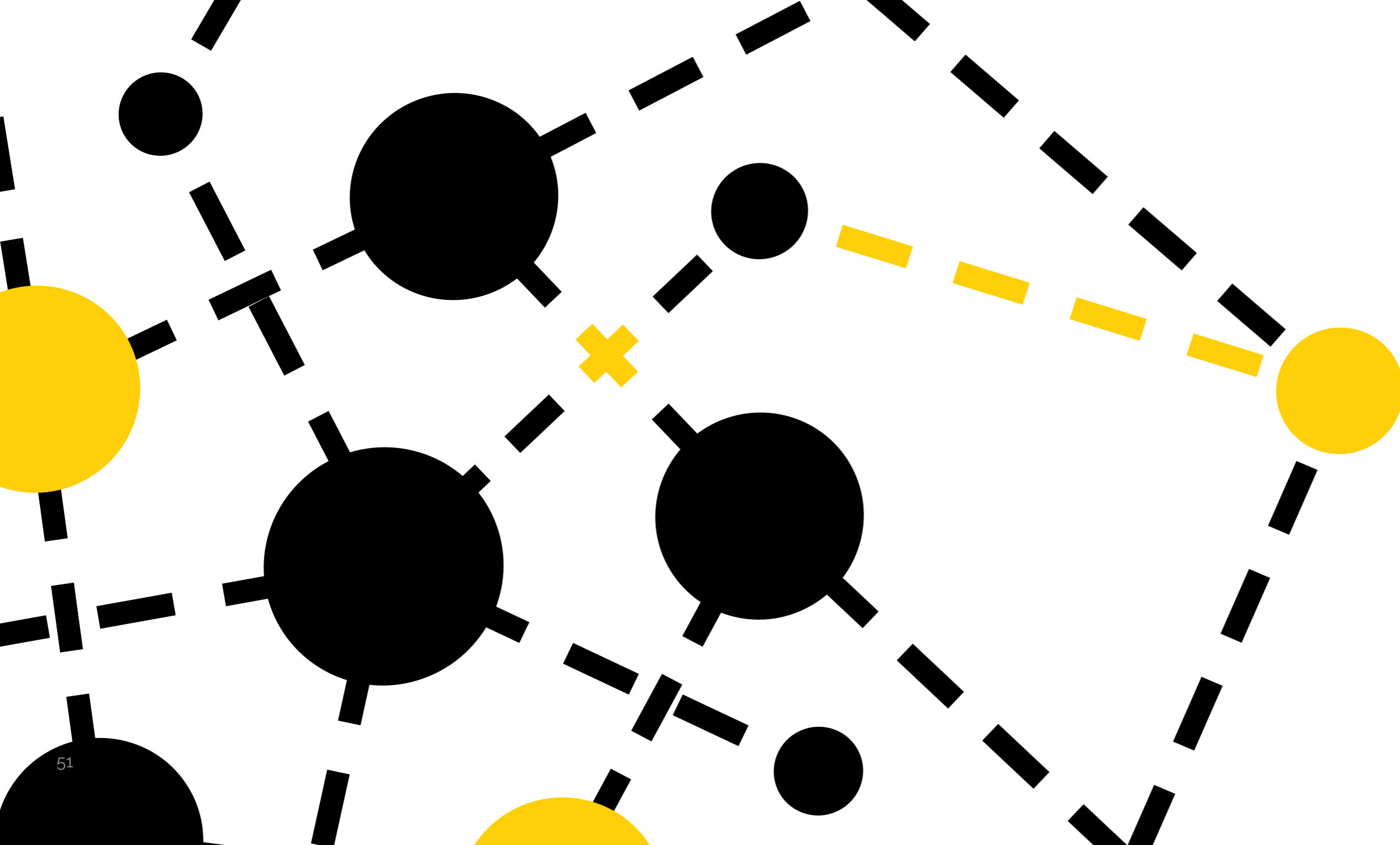
WIDELY VARYING DEFINITIONS OF **SUCCESS**

Delivering these treatments and looking after people with CF is a complex task. Recent developments have meant much better quality and length of life for people with CF, yet there are still many challenges. Today's CF care is the product of a wide range of technologies, decades of accumulated medical and clinical breakthroughs, pharmaceutical research, and political innovations required to set up and run public healthcare. This map looks at the relationships between some of the actors involved in delivering care and shows how value, attitudes, and knowledge moves around this network.

Of course healthcare is more complex than this diagram can demonstrate. Yet, even when beginning to map these connections from my research, it quickly emerges that its actors have very different motivations and definitions of success and value - sometimes complementary, sometimes clashing. Moreover, there are power imbalances, and often the bigger picture at system level does not figure into everyday work carried out in isolation. This means that change and innovation within this network can be expensive and slow, and only reflect a few particular interests.

Expert Interviews

To get a closer view of this system and explore different angles and viewpoints in more detail, I interviewed a range of people involved in diverse parts of the healthcare network.

As already shown in the system map above, they paint a picture of a complex system with many diverse actors, each with different interests, knowledge, and definitions of values - who sometimes clash, sometimes complement each other, or act insularly. They also talked about ways in which their own work has been changing and where future opportunities might lie. Much of it seems to happen outside the public health realm, and in isolation rather than being a coherent effort at moving things forward.

Case Studies

To find out about emerging trends I also looked at case studies within and beyond healthcare, where the traditional one-dimensional view of how to address disability and chronic illness have been challenged. They complicate these questions, break down the patient / expert dichotomy, open up possibilites, and allow hackability.

(for more detailed interview and case study summaries see appendix p. 18 - 27)

Emerging Trends in Healtcare

To shed more light on where things are headed, I complemented this with further secondary research on what is happening at the cutting edge of healthcare and what the future might look like in this space. This is a summary of interrelated emerging trends within and beyond healthcare.

(This is based on readings listed in 'Cystic Fibrosis and Healthcare', appendix p. 9 and analysing case studies described in more detail in appendix p. 22)

Precision Medicine

Medical knowledge is based on the average response to particular treatments. Today there are more and more programmes collecting and interpreting genomic data that can explain these differences, predict patient's responses to treatment, and help to develop precise and personalised medicine. These tests are becoming cheaper, quicker, and more portable too.

Portable Digital Health

New digital technologies allow people to track and analyse their own everyday health data through wearables and smartphone apps. This and other health knowledge can be shared with others, or used to make lifestyle changes.

Digital Public Spaces

Patients demand transparency regarding their health records, and turn to the internet for advice and support from peers. Patient organisations act as spaces of innovation and move from passive provider of data or fundraiser to being actively engaged in the process of producing and circulating knowledge. Online crowdfunding is used to finance clinical trials for rare diseases, and we have seen the gamification of treatments and healthy choices through apps.

More Than Medicine

The importance of healthy lifestyles has been recognised within and without the medical profession. Giving people the skills, knowledge, and confidence to improve their health and well-being, and emotional and practical support to live well with long-term conditions has become more important. There is a reorientation from clinical professionals as expert instructors to partners and collaborators.

To summarise, digital technology is becoming increasingly important, and this goes hand in hand with social innovation and new attitudes, needs, and behaviours. Financial aspect however, are also more and more important, and much of this is happening outside of public healthcare, in a more private and commercial setting.

Many questions remain unanswered, especially in the area of consent, privacy, and sharing data. As well as around the ethics of funding new and innovative research, drugs, and treatments within a system that includes both public health and a capitalist market. It is also worth taking a critical view on the usefulness of more and more data gathering, and whether we really are producing new kinds of knowledge and using it differently from before. The role of the patient in all of this is becoming increasingly blurred and contested from all sides of the healthcare system, including patients themselves.

People with CF

Working at the Extremes

The aim of this project is to explore some of these questions relating to the future of healthcare through the lens of living with CF. The complex and life-long treatment regime, frequent hospital stays, personal involvement in large parts of their own care, and new possibilities for precision medicine make people with CF extreme users of the healthcare system. Thus CF is an interesting case to highlight key dimensions and to provide deep insights (Boyer et al, 2013: 53).

People with CF...

...are usually very involved and proactive in their own daily care

...blur and challenge one-dimensional views of health and illness

...are usually also involved in creating knowledge used to treat CF

... work with multi-disciplinary medical teams to manage symptoms

...cannot meet each other in person due to risk of cross-infection

...rely on the internet for contact with peers, and there is a lively community of people with CF supporting each other and advocating their position

...are at the cutting edge of research with new treatments being developed and tested, as new technologies such as gene editing are becoming available

...are at the cutting edge of debates and campaigns around funding innovative drugs with NICE rejecting to fund the life-changing but extremely expensive treatment Orkambi

Landscape

Looking at this system from the perspective of someone with CF as extreme user, reveals a much larger view of what health and illness means. It quickly develops into a map of the wider landscape someone with CF is surrounded by and helps to understand deeper impacts. This shows that looking at health and care on a macro level and in a social context can reveal more insights than considering it micro and individual.

Appointment Journey

When looking at the other extreme and zooming in, it becomes clear that there are moments of intensity within this landscape - for example a hospital check-up. And yet they leave little space and time to make sense of and discuss the bigger picture. What do these test res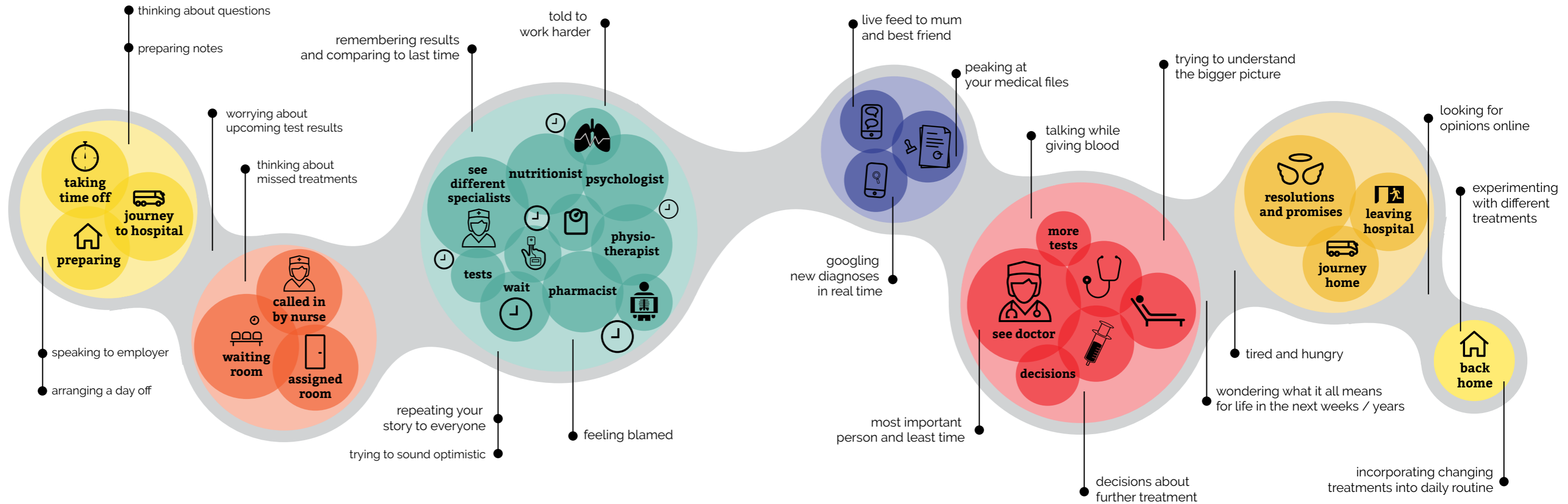ults mean for my job, my family, my life from now on? Do I need to put more work into getting better or arrange myself with the new situation? What if I feel different from what the tests suggest? When will I die?

thinking about questions

preparing notes

remembering results and comparing to last time

told to work harder

live feed to mum and best friend

peaking at your medical files

trying to understand the bigger picture

worrying about upcoming test results

thinking about missed treatments

looking for opinions online

taking time off

journey to hospital

preparing

see different specialists

nutritionist

psychologist

physio-therapist

tests

wait

pharmacist

talking while giving blood

resolutions and promises

leaving hospital

experimenting with different treatments

speaking to employer

arranging a day off

called in by nurse

waiting room

assigned room

journey home

repeating your story to everyone

trying to sound optimistic

feeling blamed

googling new diagnoses in real time

more tests

see doctor

decisions

tired and hungry

back home

most important person and least time

wondering what it all means for life in the next weeks / years

decisions about further treatment

incorporating changing treatments into daily routine

61

62

A total of 85 people completed the questionnaire. There were more females among the respondents than males (61.2% versus 38.8%). Respondents ranged in age from 16 to 65 and the median age was 30. The majority of respondents (73%) were aged 20-40.

25% of individuals said that their doctor/CF care team had provided them with information on their life expectancy as part of their routine care, while 66% had not been provided with such information and 9% were not sure.

27% of individuals had actively sought information on life expectancy from their doctor/CF care team and 74% of those had actually received some information.

71% of individuals had sought information on their life expectancy from sources other than their doctor/CF care team. Over 25% of respondents had sought information on their life expectancy from each of the following sources: "Reports from the Cystic Fibrosis Trust/the Cystic Fibrosis Trust website" (41%), "Research literature" (39%), "Patient websites/forums" (29%), "Other internet sites" (26%).
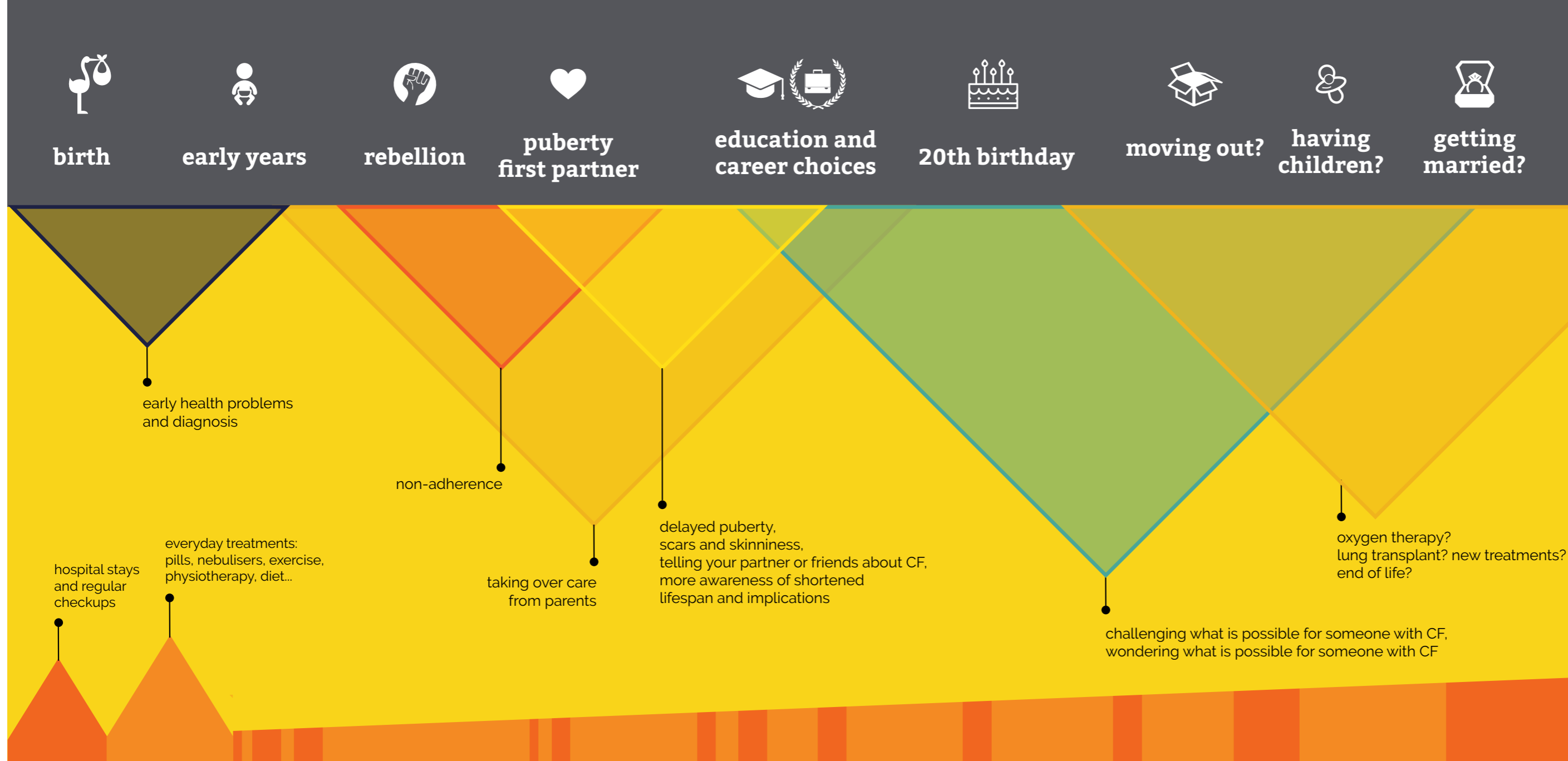
73% of respondents reported that they would like to receive more personalised information about their life expectancy. Of these, 40% would prefer to receive this information only from their doctor/CF care team, 32% would prefer to receive it only by themselves, for example via an online tool, and 27.4% would like to receive such information both/either from their doctor and by themselves.

Life Expectancy Survey

In fact, many people with CF would like to know more about their life expectancy. To illustrate this, Dr Ruth Keogh, Associate Professor at the London School of Hygiene and Tropical Medicine, has kindly allowed me to include a preview selection of her results from a survey to understand what people with CF would like to learn about their life expectancy and other outcomes.

Knowing about life expectancy can be a useful resource in the pursuit of a life well lived, and there are more and more options to arrive at reliable estimates. Yet these more human questions often remain difficult to discuss with doctors and within the healthcare system with its focus on diagnosis and treatment.

(for more information see appendix p. 28 or http://blogs.lshtm.ac.uk/ruthkeogh/ cf-online-questionnaire/ for details of the questions and upcoming results)

Life Journey

Living

With CF

| birth | early years | rebellion | puberty first partner | education and career choices | 20th birthday | moving out? | having children? | getting married? |

It is however these questions that matter when it comes to managing a whole life with CF as this example of a life journey illustrates. Ill health, early death, extensive treatment regimes, and frequent hospital stays quickly become part of all important decisions. With time, life turns into an ever bigger question mark, and into a negotiation with your body and the institutions looking after it. It might be difficult to discuss this with anyone without breaking taboos, or causing fear and worry to loved ones. Making decisions and thinking about the future can thus be characterised by loneliness and uncertainty. And yet, there is plenty of creativity, courage, resilience, and resourcefulness to be encountered in lives with CF.

early health problems and diagnosis

non-adherence

delayed puberty,
scars and skinniness,
telling your partner or friends about CF,
more awareness of shortened
lifespan and implications

hospital stays
and regular
checkups

everyday treatments:
pills, nebulisers, exercise,
physiotherapy, diet...

taking over care
from parents

oxygen therapy?
lung transplant? new treatments?
end of life?

challenging what is possible for someone with CF,
wondering what is possible for someone with CF

I may be
chronically ill....

but i'm also
chronically
FABULOUS !

somee cards
user card

The CF community online

People with CF increasingly connect to each other and the 'CF community' has changed and developed considerably over the last years. Increasing life expectancy, and the advent of the internet and social media - where people can connect without meeting physically and risk cross-infection - have created new options for peer support within an adult patient community. Digital ethnography can reveal glimpses of this online world, and this is an impression of how people make sense of their lives with CF in the digital public space.

This online space is mobilising an adult patient community who increasingly use their experience and clinical knowledge to make themselves part of the networks of experts dealing with CF. Patient organisations like the CF Trust increasingly move from fundraiser and passive provider of data to becoming engaged in the process of producing and circulating knowledge that is critical to people with CF.

These developments are not without conflict, resistance, and limitations, but overall patient organisations often innovate the relations between citizens and research, public health, and industry. They work within these systems to imagine new appraisals of their causes and conditions and this constitutes a new form of citizenship based on the collective production of knowledge.

(For examples, quotes, and summaries from exploring the digital spaces around CF see appendix p. 34)

Close-Up

To explore in more detail how digital and non-digital interactions between people with CF might look like today, and what difference they make within a life journey, I interviewed Oli Rayner who lives with CF. This is of course only one case, but it provides a close-up view of the issues mentioned above.

It shows that being in touch with others with CF is a complex issue and has both upsides and downsides. It can be extremely upsetting, especially when it has been mediated through media with its own interests in portraying people a certain way. Recent developments have meant a more inspiring, positive impact is possible with longer and fuller lives, more direct connections, and continuously changing possibilities. Still the balancing act of living with CF but not letting it take over life completely, also applies to connecting to others with CF.

(for full transcript see appendix p. 30)

Design Response

What if...?

What if connections between people with CF became an important resource for understanding, inspiration, and support? And help people with CF to help others, to make a valuable contribution to someone else's life, and to leave a legacy.

What if spontaneous and one-off connections could complement personal relationships so that editing and sugar-coating how you feel to not upset loved ones does not become overbearing?

Collecting more health data can be useful. But how might this data be used to create knowledge, or even meaning? What if it could help us to live adventurously and remarkably? What if it could help us accept uncertainty, but encourage us to make decisions reflecting hope not fear?

Medical and pharmaceutical improvements are essential to CF care, but there are a number of questions they cannot answer. How might we instead acknowledge, encourage, and make use of the resourcefulness, resilience, courage, and creativity people with CF live their lives with?

A Possible Response

Compass - An app for wayfinding. This app will let people with CF get in touch with others who live with similar health challenges. A phone call provides a direct, personal, but non-committal way of contact.
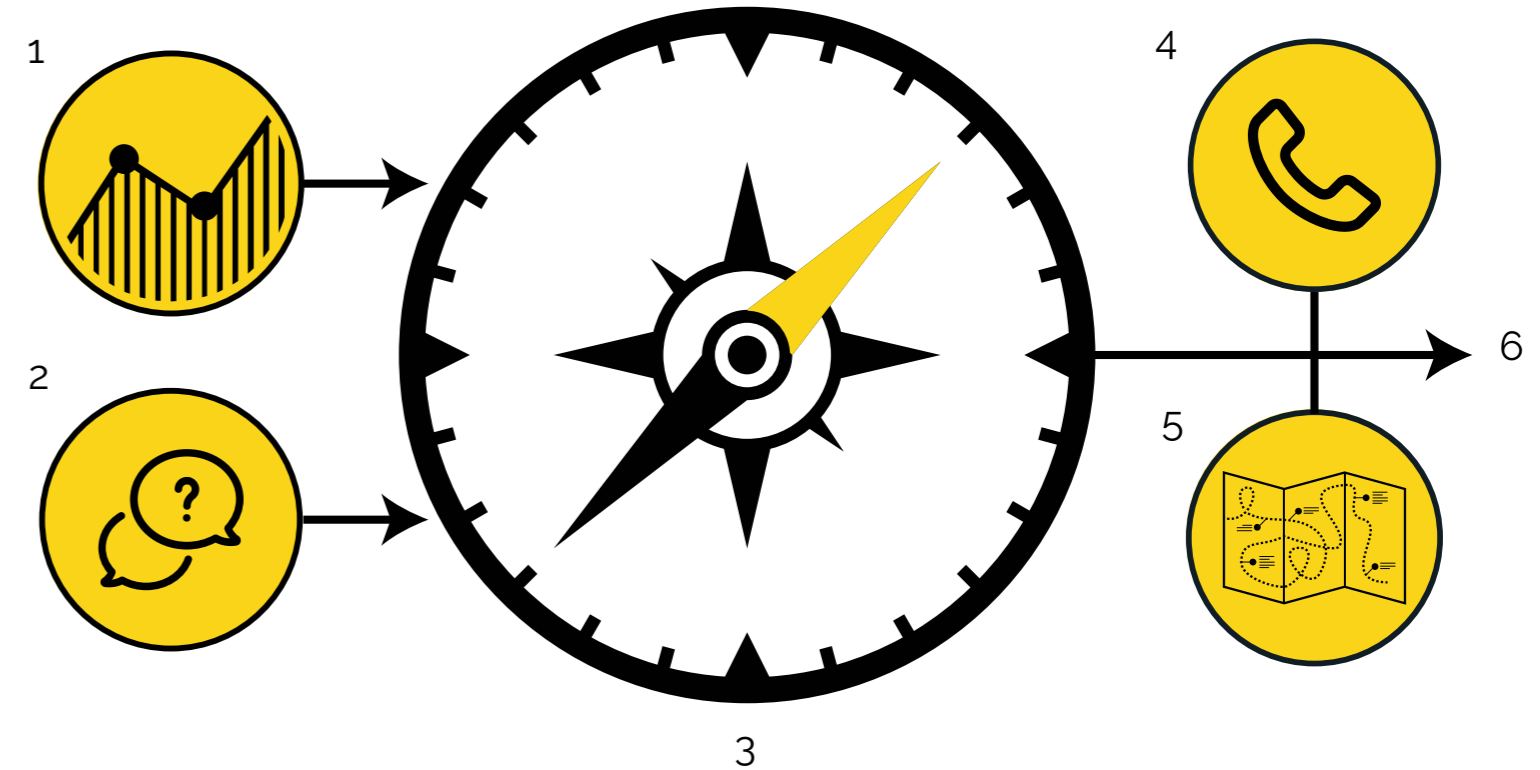
It also lets people explore logs of other people's journeys with CF and beyond. And reflect on and log their own journey.

Compass bridges the gap between medical and measurable data, patient activism, and research - and the more human layer of well-being, sensemaking and wayfinding through storytelling and personal contact.
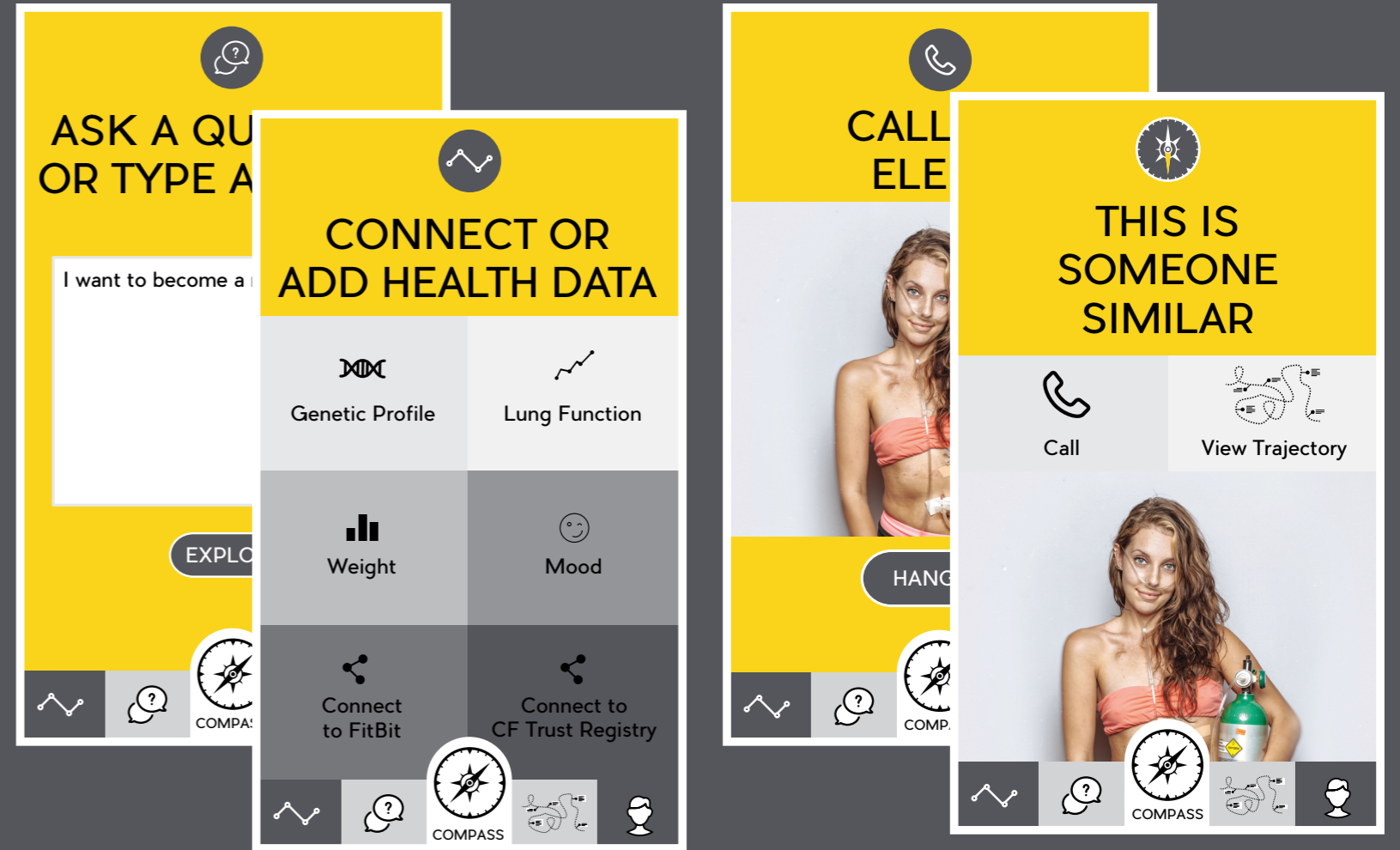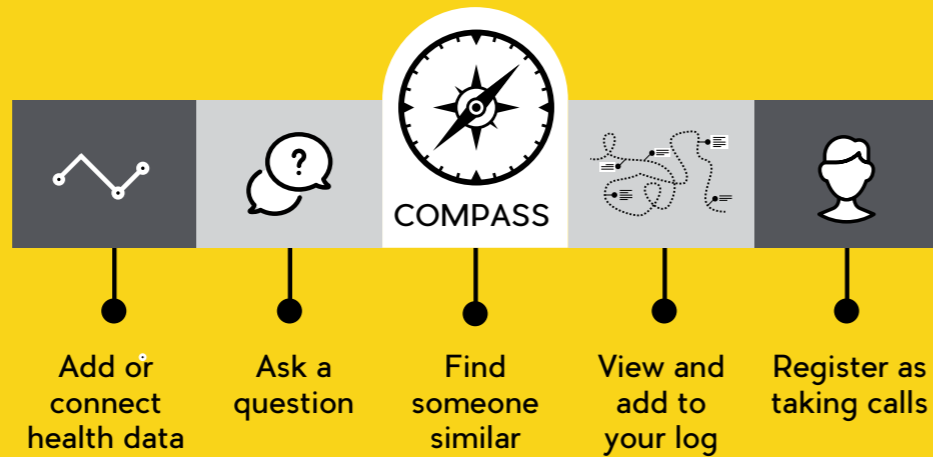
1 Share (some of) your data with Compass,

2 You can also add a question.

3 Based on this, Compass will point you to others who had or are having a similar experience, challenge, or question, or live their lives in a body similar to yours.

4 It will offer you the possibility to start a phone call with this person. It is spontaneous and what you make of it, no strings attached.

5 You can also view a mapped trajectory of this person's life, a brief log of events, experiences, ideas.

6 If you would like to, you can register your phone number with Compass to also be available for calls. To share (some of) your health data. And to log your own journey.

COMPASS
A WAYFINDING APP

COMPASS
A WAYFINDING APP

COMPASS
A WAY FINDING APP

COMPASS

| Add or connect health data | Ask a question | Find someone similar | View and add to your log | Register as taking calls |

ASK A QU
OR TYPE A

I want to become a

EXPLO

CONNECT OR
ADD HEALTH DATA

Genetic Profile	Lung Function
Weight	Mood
Connect to FitBit	Connect to CF Trust Registry

COMPASS

CALL
ELE

HAN

COMPASS

THIS IS
SOMEONE
SIMILAR

| Call | View Trajectory |

COMPASS

EXPLORE TRAJECTORY

HELENA'S JOURNEY

FEV1
up!

gave birth

very tired

trans plant

COMPASS

LOG YOUR OWN JOURNEY

YOUR JOURNEY

add   add   add

COMPASS

REGISTER TO RECEIVE CALLS

Ute

CONFIRM

COMPASS

What data should be revealed to whom? What does / did it mean for daily life, and for the bigger questions?

What is a life well lived? What is possible? What is important?

What gets me through? What keeps me happy? What difference did something make?

More Questions

Compass does not intend to provide answers, but show possible trajectories, challenge what might be seen as inevitable or impossible, and open up discussions.

This applies to living with CF, as well as to broader issues of sharing medical data, of how health knowledge is defined and controlled, and what it means for quality of life.

These are some of the questions people with CF might ask when using the Compass app.

Testing and Reflection

To prototype and test this design concept, I e-mailed a blogger who also lives with CF and is around the same age as me. I briefly outlined the idea, and pointed out that there is a question close both of us seem to ponder frequently in relation to CF: What about doing a PhD? I knew this from her blog posts, and we arranged a phone call. The phone call lasted 11 minutes and 32 seconds. I asked her to e-mail me her thoughts after:

"The first thing I noticed is that you make the same noise mid-sentence, the one when you take a strategic breathing pause and clear your throat of annoying mucus. I didn't know other people did this! It was such a strange experience recognising this, like hearing a lost sibling."

"I felt free. I didn't have to hide or be overly positive, and I could just mention potentially dying young. In fact, I didn't really have to mention it or spill it out, we both know. It was a relief to talk like this."
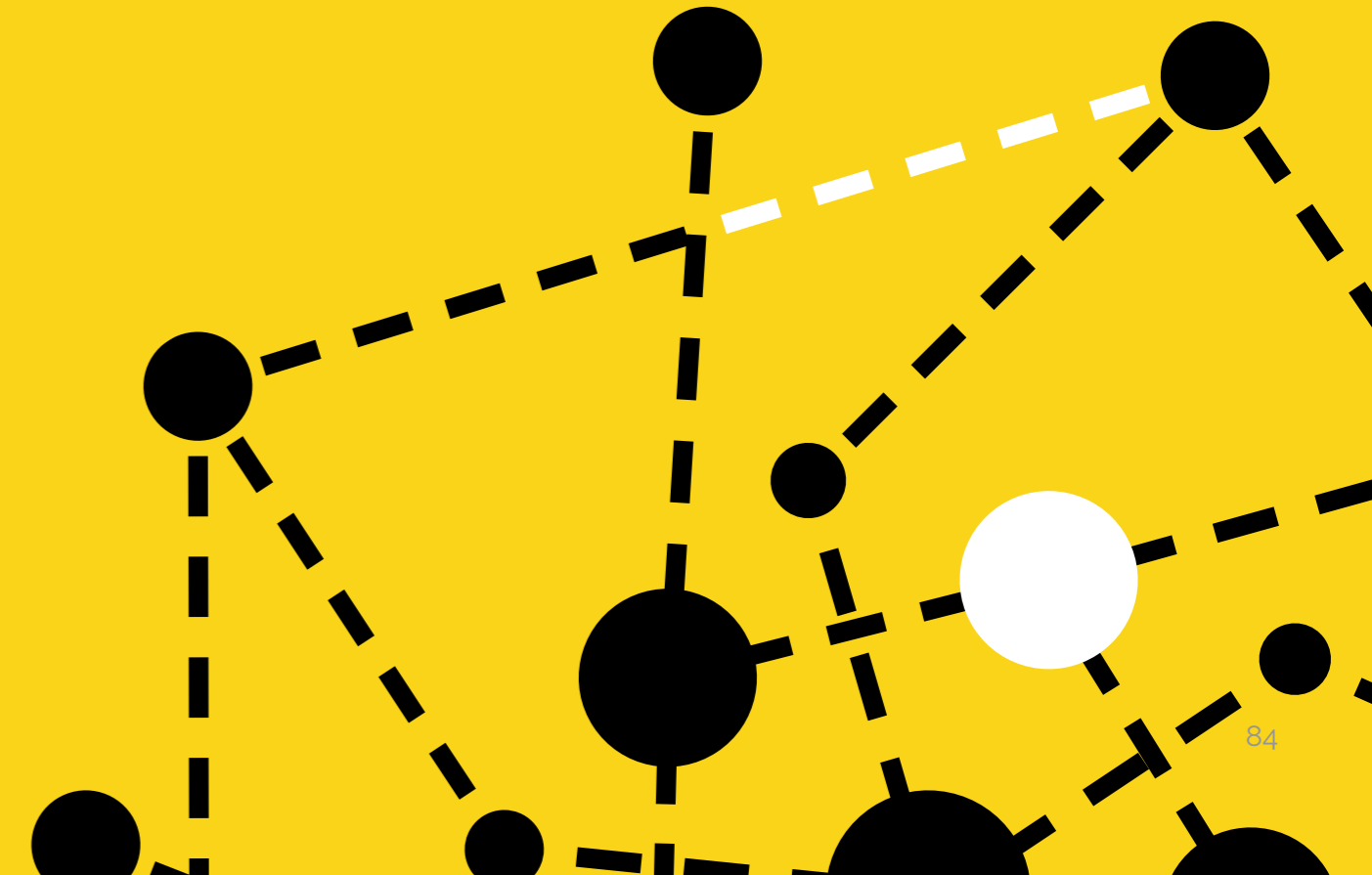
"We came up with some new points I hadn't thought of before. But the main thing I loved was that actually we didn't talk all that long about if it is possible, we quickly moved over to HOW it could be done. And wondering who might have done it, and what their health was like."

"I was less worried you might laugh at my ideas or just make that worried face and tell me it will not be good for my health. My doctors' and family's opinion is really important to me, but sometimes you just need someone to understand that there are other things you need to be happy not only healthy."

Of course this is at best an approximation of the concept described above, but I was excited to test it and curious about my own and my phone partner's experience and reaction. And it was very positive, for both of us. It would be interesting how this concept could integrate with new developments like the CF Trust Registry (appendix p. 18), or their initiatives around digital health. Given more time, it would be interesting to find out if Compass connected people with similar life expectancy estimates, as well as to hear how other parts of the healthcare system relate to this idea. And how the idea behind Compass could apply to wider healthcare contexts where relationships are changing, and where data is playing an increasing role, to add a layer of meaning, sensemaking, and wayfinding.

Appendix

This includes references to other people's work that shaped this project, as well as some of the data I collected during my own research in more detail.

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Image Credit

IAN PETTIGREW   http://www.ianpettigrew.com/

Photographer Ian Pettigrew - who has CF himself - took portraits of women with CF for his book Salty Girls. It turned into an incredibly inspiring and powerful project that has made a huge difference to how I see myself as a person with CF and enjoyed worldwide attention. Ian generously allowed me to use his photos within my work. I am very grateful to him and the salty girls Bailey (Book 1, p. 16), Erin (Book 1, p. 19), and Amy (Book 1, p. 33).

Salty Girls
Imagine what it is like growing up as a woman in today's society, where the media demands perfection, and where body-shaming has become all too prevalent. It is a constant struggle to maintain the concept of 'beauty'. In this book the Salty Girls challenge this norm, and strive to put an end to body shaming. They embrace their body's scars and all, to inspire women everywhere to do the same. These women truly are the epitome of remarkable strength, enormous resilience, and unique beauty both inside and out. Not only is this book about raising awareness for Cystic Fibrosis, but it can truly reach all females who have ever felt this way.

Expert
Interview
Summaries

Euan Cameron

**Director of Cohesion Medical -
collaborative software for clinics
which records and manages
data, and measures and
evaluates treatment outcomes**

To address this, the culture
and mindsets of the actors
are important, the focus
should be reframing
their relationships.

The actors within healthcare
are so insular and
fragmented that we can
hardly speak of a
healthcare 'system'.

Within healthcare, both
ethical and monetary value
has to be considered.

Karen Glen

**Former Field Sales
Manager at a large
pharmaceutical company**

The extreme commercial
orientation of pharma
companies can be in conflict
with other parts of the
healthcare system.

Mindsets are beginning to
shift, but public service is
slow and rigid when it comes
to change.

Expectations between
actors within healthcare still
play a large role and can
feed frustration.

Justine Gangneux

**researcher working on
surveillance, digital
technologies, and
social media**

The positive and negative
sides of the quantified self
movement - collecting data
on daily life through
technology and wearables -
is especially complex in the
healthcare context.

Self-monitoring has
become ubiquitous and in
future we will have to ask
questions about who we
share this data with and how
we use it.

Katie Walsh

designs crowdbased activities for innovation agency 100% Open, e.g. the CF collaboration platform 'Hack It Up'

■

Peer support is increasingly important for chronic illnesses.

■

Yet engaging patients needs continuous leadership.

■

It's expensive to manage and keep up interest and participation.

Fergal Coulter

researcher experimenting with 3D printing artificial muscles

■

The experience of patients is vital when framing a problem. And tools or hacks developed by patients are very interesting in this respect.

■

Healthcare is a difficult space when it comes to innovation, it moves very slowly.

Kimberly Yong

junior doctor at NHS Glasgow

■

There is a new focus on quality of life as aim rather than extending a person's lifespan. Doctors are encouraged to take a step back and ask if invasive treatment would really benefit a patient.

■

There are also steps towards having these conversations with patients, and encouraging them to make decisions early for when their health declines, so they can have a say.

■

During training, there is a new focus on autonomy, on letting patients decide what happens to them (within reason), even if this means declining treat.ment

Rebecca Cosgriff

responsible for the CF Trust's Registry - a secure online database collecting clinical data with exciting new developments

■

Tech and social innovation normally build on each other. A software update means the registry can meet the evolving needs of a dynamic and informed population. The new Registry is about transparency, fairness, and proactiveness. It will be a powerful resource for research, tracking impact, and driving innovation. And a day to day help giving feedback to clinical teams and people with CF. They will have access to their data and can add to it, collecting new kinds of evidence relating to e.g. quality of life.

Case Study Summaries

CF Research News - Medical papers in plain language

CF Research News publishes plain language versions of scientific work from the Journal of Cystic Fibrosis in pdf format. They aim to bridge the gap between people with CF and the researchers investigating CF and how best to treat those with the condition. They hope to reach patients, parents, relatives, friends, and caregivers.

European
CF Society
ecfs.eu

Computer games that heal you

Imagine if you could play a computer game that healed you as you played. Sounds far-fetched? Computer game therapy is a growing field that is still finding its feet. But my prediction is that 2016 will be the year that doctors start prescribing games to patients.

Nesta
nesta.org.uk

Post / Biotics Toolkit - What if the next antibiotic is in your backyard?

A new toolkit called Post/Biotics is designed to let citizen scientists —including elementary school students—help in the process of discovering those new drugs. It includes a small pop-up lab that anyone can use to test samples and then send results, along with a photo and GPS location, to an online database. Citizen scientists test their samples against non-pathogenic bacteria strains provided with the toolkit.

Post Biotics
post-biotics.com

Mia Cinelli's limb like weighted blanket is designed to ease feelings of grief

Following the death of a loved one, American artist and designer Mia Cinelli created this 'weighted comfort object' that could simulate the feeling of being hugged.

Mia Cinelli
miacinelli.com/The-Weight

Breath Cycle - Singing and Cystic Fibrosis

Scottish Opera and Gartnavel General Hospital Cystic Fibrosis Service have been working together since early 2013 to explore whether learning classical singing techniques, including breath control, can improve the wellbeing of cystic fibrosis patients. Due to the high risk of infection for those with cystic fibrosis, the project also explored how patients might interact safely with each other, using the internet as a means of meeting, learning and building new communities.

■ NHS & Scottish Opera
breathcycle.com

The Blazer Experiment - On how police uniforms represent their relations with the community

In 1968, the police department in Menlo Park, California decided to reform the department. Its chief wanted to rebuild trust with the community — and one of the most ground-breaking and controversial changes was the new blazer-style uniform he implemented. It tried to change how police are seen and see themselves. But can a new uniform really change the culture of a whole police department?

■ Menlo Park Police department
99percentinvisible.org/episode/the-blazer-experiment/

Quanitified Self - self knowledge through numbers

A movement consisting of user communities of self-tracking tools. They aim to build a culture of access to one's own personal data and of exploring the benefits of shared self-collected data to solve complex health challenges.

■ Quantified Self
quantifiedself.com

'Making Health' - a celebration of how tinkering, technology, and design tools are transforming healthcare

An event bringing together clinicians, scientists, inventors, and makers to explore how do-it-yourself, design tools, and technology can quickly transform ideas to working prototypes and innovate healthcare.

■ US National Insitutes of Health NIH
medstarhealth.org

E-Patients - because health professionals can't do it alone

A movement advocating and facilitating participatory medicine. This is a model of cooperative health care that seeks to achieve active involvement by patients, professionals, caregivers, and others across the continuum of care on all issues related to an individual's health. Participatory medicine is an ethical approach to care that also holds promise to improve outcomes, reduce medical errors, increase patient satisfaction and improve the cost of care.

■ E-Patients
e-patients.net

Do it yourself pancreas - we are not waiting

Using a raspberry pi and publishing the DIY blueprints, Dana Lewis has built her own artificial pancreas system. Tapping into the potential of patient innovators and independent researchers, she started a movement of DIY pancreas builder who refuse to wait until similar technology has been FDA approved and commercialized through traditional processes. They often mean expensive solutions that do not take the dignity of the patient into account.

■ Open APS
openaps.org

Cystic Fibrosis Priority Setting Partnership

In CF care there are many situations where we do not know which treatment is best. Over 300 important research questions are currently unanswered. Presently researchers choose their projects because they are fashionable, of personal interest or of interest to funders including the pharmaceutical industry. The priorities of patients, carers and clinicians are often overlooked. By involving in producing a priority list of uncertainties important to them, this projects aims to change this.

■ CF Unite
cfunite.org

The Swedish Number - get connected to a random Swede and talk about anything

An initiative by the Swedish Tourist Association, this project encourages people to find out more about Sweden in a playful and personal way. With a total of 187632 incoming calls in the 79 days it was open for, it has proved to successfully tap into people's curiosity.

■ Swedish Tourist Association
theswedishnumber.com

Life Expectancy Survey

DR RUTH KEOGH
http://blogs.lshtm.ac.uk/ruthkeogh/

Dr Ruth Keogh - researcher at the London School of Hygiene and Tropical Medicine - is doing very interesting research to understand what people with CF would like learn about their life expectancy, how they would like to do so, and how things are at the moment.

It was very encouraging to find out about a thought provoking and considered project dealing with the more social but just as challenging side of life with CF. Dr Keogh kindly provided me with a preview of the results from her survey (Book 1, p. 38), and details of the questions and upcoming results can be found here:

http://blogs.lshtm.ac.uk/ruthkeogh/cf-online-questionnaire/

A selection of results from the "Online survey to gain understanding of what people with cystic fibrosis aged 16+ would like to learn about their life expectancy and other outcomes"

A total of 85 people completed the questionnaire. There were more females among the respondents than males (61.2% versus 38.8%). Respondents ranged in age from 16 to 65 and the median age was 30. The majority of respondents (73%) were aged 20-40.

25% of individuals said that their doctor/CF care team had provided them with information on their life expectancy as part of their routine care, while 66% had not been provided with such information and 9% were not sure.

27% of individuals had actively sought information on life expectancy from their doctor/CF care team and 74% of those had actually received some information.

71% of individuals had sought information on their life expectancy from sources other than their doctor/CF care team. Over 25% of respondents had sought information on their life expectancy from each of the following sources: "Reports from the Cystic Fibrosis Trust/the Cystic Fibrosis Trust website" (41%), "Research literature" (39%), "Patient websites/forums" (29%), "Other internet sites" (26%).

73% of respondents reported that they would like to receive more personalised information about their life expectancy. Of these, 40% would prefer to receive this information only from their doctor/CF care team, 32% would prefer to receive it only by themselves, for example via an online tool, and 27.4% would like to receive such information both/either from their doctor and by themselves.

Interview with Oli Rayner who lives with CF

Are you regularly in touch with other people with CF, and if yes, how? (E-mail, messages, phone calls, in person...)

I was born in 1975 and so when I was growing up we did not have the internet, social media, skype or mobile phones. I only started using email when I got to university in 2004. Even when new technology came along I avoided talking to other people with CF outside the hospital environment because all the people with CF I'd got to know when I was younger (whom I had met at hospital when less was known about cross-infection and segregation was not so strict) had passed away and I found it extremely upsetting. Also, the only time I saw anyone else with CF was either when they were sick in hospital or when there was some media coverage of a very poorly child with CF who was desperate for a transplant or access to some service/medication. I thought any contact with others with CF would just depress me. In the last 5 years or so, I think things have changed enormously. People with CF are living longer and fuller lives. Social media has made it easy to get to know lots of other people with CF of all ages and all backgrounds and see people doing really well at things as well as not so well. It is not all bad news now. I am now in regular contact with others with CF and I use different media for different purposes. Typically, I would probably "meet" new people with CF through social media and then, having developed a level of trust and mutual interest, I would also use email, telephone, text, WhatsApp and Skype-like tools.

If yes, why do you keep in touch and what difference does this make to you? If no, why not, or what holds you back?

I talk to others with CF because it helps me to understand my disease and what it means. I suppose I am always trying to figure out "what is the CF" and "what is me"! I also like to try to help other people with CF (and young parents of children of CF) where I have some experience or perspective that might be relevant to them. It is always good to share problems to see if it is a more general issue that we can solve together or, indeed, find out if someone else has already come up with a solution and can share know-how. I also do some patient advocacy both independently and with the CF Trust and building relationships with others with CF and understanding how they feel about things is really important because CF affects different people in different ways and it is important to know what really matters to peers and whether views are representative or more subjective. If I am in a meeting or at an event (and I am the only person with CF able to be there due to cross-infection) I often feel a heavy responsibility to represent a wider point of view rather than just my own.

I suppose I do hold myself back a bit because I don't want CF stuff to dominate my life too much and I suppose I am still reluctant to get to know anyone with CF too well because of my earlier experience of CF friends passing away.

Do you have any 'CF idols' - people with CF you know about and you look up to? What does this mean to you?

I never used to know anyone with CF who was doing well when I was younger. In the last 5 years I have become aware of several pwCF who are doing really well and I do admire what they do. I would not call them idols but sometimes they do inspire and reassure me. Seeing people with CF do well makes me feel stronger. I also get a lot of pleasure from seeing others with CF doing well in life because it seems to signify progress and I love the idea of progress! I won't name names but some of them have become friends. Some of them are professional sports people, fitness gurus or champion bodybuilders which is fun to see but the ones I really admire are those who have built a life for themselves and managed to integrate a career, family and taking care of their health. I think those people are the most impressive. I hate to think kids with CF see the bodybuilder types and are left with the impression that they can do well with CF but only if they become a bodybuilder. I hope one day kids with CF can look around and see that CF is compatible with normal life as long as they are sensible and prepared to work a bit harder that others.

How do you make or have you made decisions concerning your future? Do you consult doctors / friends / other people with CF / ... when you think about what is possible when living with CF?

I have never really thought about what is possible living with CF. When I was born my parents were told I would not make it to 10. When I was 10, we were told I would not make to 16. When I was 16, my CF consultant told me I would be lucky to get to 25 and that I would need a heart and lung transplant by 21. Based on this, the pace of medical progress and my experience of how different people are affected differently, I don't think anyone can say with any confidence what life with CF will be like. I have always just tried to understand what I can do and what I cannot do and I use that to plan what I will do. When my capabilities change, I try to figure out whether it is a new normal or just a bad patch and, if necessary, I change my plans. I have had to adapt my life/work several times over the years, especially since CF started to affect me much more from my early 30s. I talk to my CF team, family and close friends. I had some useful discussions with tutors at Uni. I have also had some very useful conversations and advice from work colleagues over the years – I have always been very open with employers about my CF. I don't talk to others with CF very much about persona decisions/plans because none of them know me well enough.

Impressions from Digital Ethnography

"However, it is difficult to be an adult - to be married, to work, to better myself, and to plan for the future - all while managing a complex and time-consuming chronic disease with no guarantees. I fail more than I succeed, but I plan to enjoy every single day I wake up with breath."

"Even if you are in pain, often the physical pain is less than the psychological pain and fear that comes with dreading what the future might bring."

"You are not completely healthy at this point on the horizontal axis of time. Yes, your body has weird and unusual chloride channels lining its epithelium. But is your brain 'sick'? Is your heart 'sick'? Are our bones intact? Can you see? Are you breathing? Can you love?"

"The photo reminds me of a lesson I need to be mindful of every single day. That lesson is the notion that we can plan or dream of the way we want our lives, our time, or our energy to be spent, but in reality sometimes, our ideas will never come to fruition despite our efforts."

"The CF Trust is focused on getting the magic pill, but in the process, has it neglected and ignored what we would call the rest of our 'quality of life'".

"But life is not all about the numbers of tomorrows... it is also important to think about the quality of those tomorrows. If I can't spend my 'tomorrows' deciding for myself how to live, then what is the point exactly?"

"Acting as my own head nurse, I decide when to hook-up, what to eat, where I can and cannot go, and who to see. I govern the controllable that inpatient care can unfortunately strip away from its guests."

"I have learned over the years to go into appointments with little expectation, that way I am able to focus on the positives of a bad appointment or celebrate the victories of a good appointment without feeling weighed down."

"Do I like taking a bazillion drugs? No. Do I like poking myself with little needles? Um, no. Do I fight fatigue? All the time. Do I always feel like I am forgetting something? You betcha. There are definitely moments where I want to throw my hands up, cry, and give up. It's exhausting to do this everyday. It is even more exhausting to do this and act like I am normal. Breaks do not exist and CF never packs a suitcase to go on vacation. I ask the Lord each day to help me find joy in those moments and thank him for

the ability to live a remarkable life in the midst of a failing body.

He grants it."

"It is in these moments that I realize how little control I have in my own body. How I spend my days strategizing and how some days that perfect strategy doesn't even come close to fruition. It is discouraging. I want to keep up with my husband and prove that I am fine, that CF plays such a small role physically that I am able to push on. In reality, this is far from the truth and my supply of oomph empties long before the project is finished usually."

"I adapted to dying, and adapted well. I had after all, spent my entire life adapting to every possible circumstance where most were out of my control."

"Sometimes I open the drawer with my daily medications and just stare at it. I can feel my body wanting to shut the drawer, erase the responsibility from my mind, and walk away to pursue something else spontaneously, instead of doing another round of therapy or choking down another handful of pills. I also know that if I did this and ignored my schedule, I wouldn't live. Weeks filled with schedules, lists, and mental alarms are a matter of life and death for me. So, I comply, sometimes begrudgingly and with an ungrateful heart."

"Our lives will always be slightly different than our peers in similar stages of life. Our priorities and goals have to be focused and planned in an effort to experience it all despite CF, and sometimes, our goals will be rewritten."

"Parker J. Palmer wrote that, 'The human soul doesn't want to be advised or fixed or saved. It simply wants to be witnessed - to be seen, heard and companioned exactly as it is.'"

"I knew it was time. It was time to take the next step in my care and that meant a portacath. The idea of having a port always weakened my soul and I was disappointed in myself. A port meant my body would be altered on the outside and I would physically look irregular. It meant I was really sick and my disease was in fact progressing. It meant I lost control and the force I battled to hold off everyday was gaining ground. It meant CF was winning and I was ultimately losing. Ports were for very sick cancer patients, certainly not for me."

"As a young girl, I was acutely aware of the difference between being treated as a patient and being treated as a human being. I had always wanted to be treated as a person who had something to contribute to society, not just as a disease. When you're a body in a bed, your sense of identity is often stripped so far back that you don't recognise yourself."

"Salty Girls has played a big part in this change. In April, I posed for a photo book about women fighting CF and the many challenges we face physically, mentally, and emotionally. It was my first time directly meeting other women with CF and knowing that we had similar scars, schedules, thoughts, fears, and never ending coughs. After the shoot, I got in the car with my husband; my heart felt full and I smiled,

"'Sorry we haven't been able to get you lungs. i'm sorry we can't save you.' I knew he had done his best and I appreciated his candour - something that had been so sorely lacking with the team who were looking after me at the hospital. That he had shared his humanness with me, as opposed to just being my doctor, meant a lot."

'They all coughed like me.' It sounds silly now, but that brief sense of community has changed me forever."

I planned my funeral. Not a common thing for a 21-year old to do, but it had been rolling around my head since I was a little girl. For me, getting that out of the way so I could focus on living was essential in getting on with life while I still had it."

"The people who did talk about dying and death were my nurses. There was this no BS thing between us, and I could talk and make inappropriate jokes about my own death to my hearts' content. But no one ever came to talk to me about dying, and for me that was disappointing because what was unfolding was really quite remarkable. And so it was something I had to do on my own.

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"I believe I have used optimism to shield people I care about (including myself) from the reality and pain of CF. Because of this, the majority of the people I surround myself with have little understanding of what having CF actually looks like. They see the sugar-coated, sunny explanation that I allow them to see, but not the dark, isolating side."

"When you have CF, you grow up dying."

Ute Schauberger

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