

Golden Years

Healthier Longer Lives in Hull



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Introduction

Welcome to my 2019 DPH report.

Directors of Public Health in England have a statutory duty to publish an annual report. These reports provide an independent voice in setting out important health and wellbeing challenges, highlighting where positive action is being taken and providing clear recommendations for further work across the system.

You can check out my five previous DPH reports including updates on their recommendations for action. Search hull.gov.uk for “DPH report”.

Hull is a proud and confident city, transformed by investment in people, place and culture, defying expectations and challenging perceptions. We have seen sustained improvements economically, socially and culturally. It's now time to build on this as we focus on ensuring that everyone benefits from a fairer and more inclusive Hull.

We are in a good place to tackle this together. Our partnerships across the city have never been stronger. We have an integrated financial plan with NHS Hull Clinical Commissioning Group (CCG) and joint decision making for all our health and social care commissioning. There are some excellent examples of integrated provision such as the Jean Bishop Integrated

Care Centre, a set of shared outcomes for health and wellbeing, and plans are in place for an Independent Fairness Commission, to begin work in 2020.

This year I wanted to use the opportunity of my DPH report to talk about population health approaches to understanding and addressing inequalities in life expectancy and healthy life expectancy because this tells us a great deal about how we are doing as a society.

In Hull, like many places in England, improvements in life expectancy have stalled. We have also seen a worsening picture in terms of healthy life expectancy and inequalities in health. The impact of this for those living with a long term condition and our society is huge. If we want to address this we need renewed effort on population health and population health management.

Population health is an approach that provides a framework for exploring ways to understand and improve physical and mental health across an entire population with a focus on four pillars: the wider determinants of health; our health behaviours and lifestyles; integrated health and care systems; and our communities. (1)

Population health management provides the information and tools to guide those developing policies and those planning, commissioning and delivering services.



Director of Public Health Annual Report 2019

In this report we explore what this means in Hull through analysis of life expectancy data in relation to the five most common causes of death in Hull. However, although this report will focus on those conditions that people most commonly die from, people will often live with them for many years in ill health. So I will also explore the impact of living with heart disease, dementia, lung disease and stroke both on the patients themselves and on their carers and loved ones.

In the final chapters I will summarise the key messages through the lens of population health approaches, set out some of the exciting opportunities we have in Hull to improve outcomes and consider areas for action across our city wide partnership.

In developing my report this year I have worked alongside some local patient groups for people who are living with a long term condition and an artist, Francesco, who was able to scribe in real time, capturing our conversation in words and pictures. These amazing visual representations can be seen throughout the report. They each capture a rich picture of the lived experience and provide some important messages about quality of life for those diagnosed and those that care for them. There are also key messages about how we could best utilise our resources to improve lived experience and health outcomes.

I am enormously grateful to all the patient groups who participated and I was really pleased to have been able to invite them to the launch of this year's report.



Context

Over the next few pages we explore a number of long term conditions that have an impact on life expectancy. We will explore four long term conditions: heart disease; dementia; lung disease, specifically cancer and Chronic Obstructive Pulmonary Disease (COPD); and stroke. We start, as we should, with the lived experience and then look at what our data tells us.

So first let's make sure we all understand what we mean when we talk about life expectancy and healthy life expectancy and why these are such important measures of inequalities overall.

Life expectancy is an estimate of how many years a person is expected to live and healthy life expectancy is an estimate of how many years they might live in a healthy state.

Figure 1 shows life expectancy at birth for men and women in Hull compared to England and Figure 2 shows healthy life expectancy at birth for men and women in Hull compared to England.

In England, improvements in life expectancy have stalled. Indeed in some places, such as Hull, we are seeing early signs of worsening life expectancy, for both men and women. Importantly, despite some small improvements in healthy life expectancy for women, we are continuing to see

men and women in Hull spending over a quarter of their life, on average, with poor health and with just under a seven-year difference to the national healthy life expectancy rate (Figure 2).

Much of this time spent in poor health is as a result of largely preventable diseases. For those who live in our most disadvantaged communities there is a double jeopardy of inequalities in health: far shorter lives spent in far poorer health.

Finally Table 1 shows the ten most common causes of death in Hull during 2015-17.

It can be seen that the top five causes of death; CHD, dementia, lung cancer, COPD and stroke, account for 45 per cent of all deaths in Hull. Additionally, with the exception of Dementia, these same diseases are the top causes of people dying under the age of 75. This is commonly considered to be a measure of premature death.

I have therefore chosen to focus this report on the top five causes of death, CHD, dementia, lung cancer, COPD and stroke and to consider the experience of those living with the conditions or those caring for them. I will also examine the trends within the city and over time and identify opportunities to prevent future cases and improve health outcomes.

Figure 1: Life Expectancy at Birth – Hull vs England

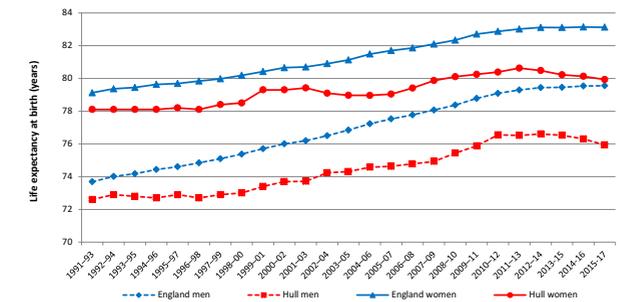
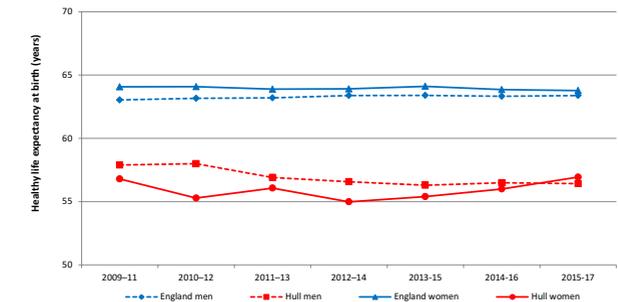


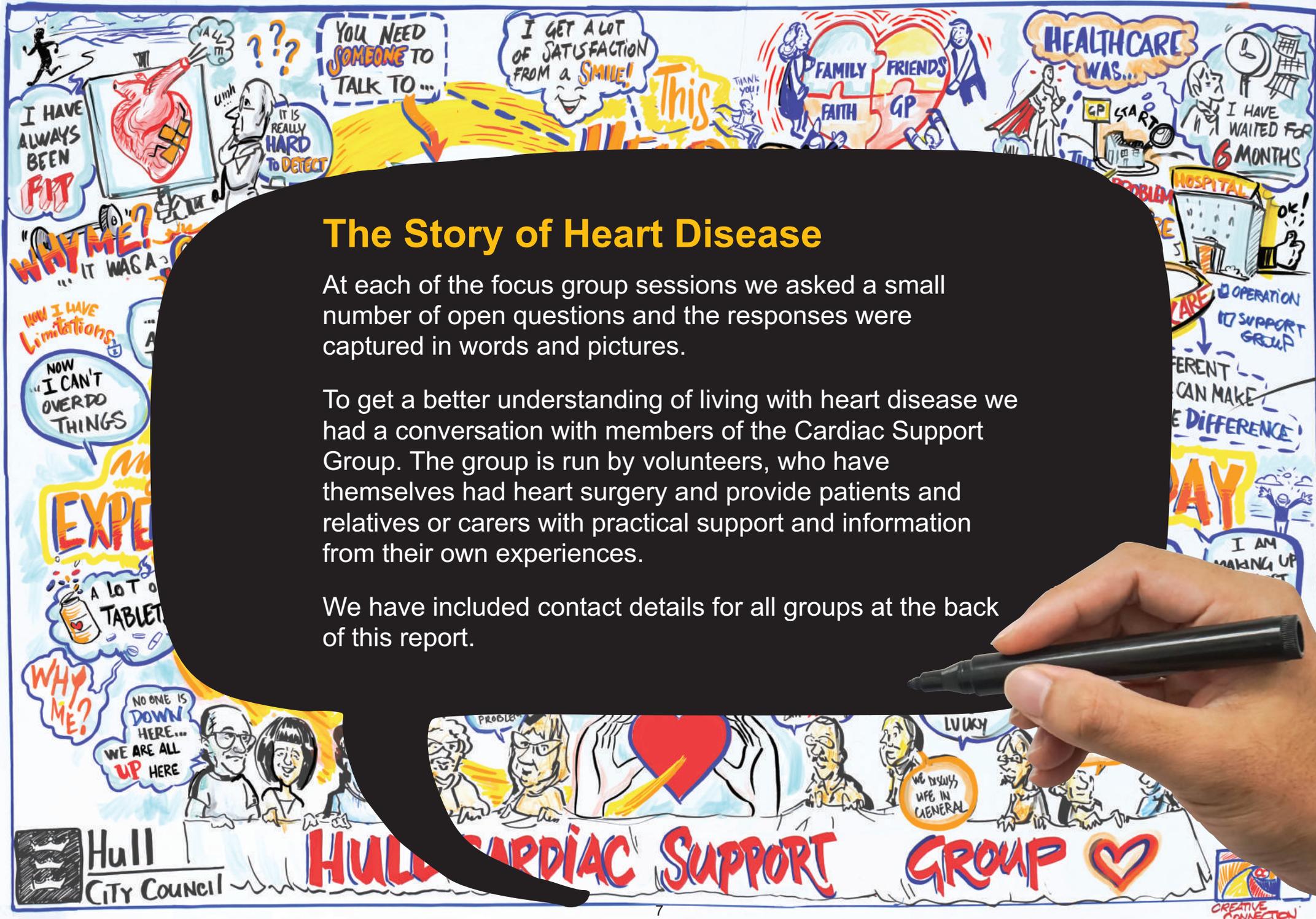
Figure 2: Healthy Life Expectancy at Birth – Hull vs England



Director of Public Health Annual Report 2019

Table 1: The ten most common causes of death in Hull 2015-17

Cause of death	All age deaths			Under 75 deaths		
	No.	Per cent of all deaths	Rank	No.	Per cent of all deaths	Rank
Coronary heart disease	920	12.0	1	347	12.0	2
Dementia	754	9.9	2	39	1.4	20
Lung cancer	641	8.4	3	352	12.2	1
COPD	602	7.9	4	216	7.5	3
Stroke	518	6.8	5	116	4.0	6
Other diseases of the circulatory system	377	4.9	6	122	4.2	4
Influenza and pneumonia	364	4.8	7	88	3.0	10
Disease of the digestive system (non-alcohol-related)	331	4.3	8	122	4.2	5
Other diseases of the respiratory system	235	3.1	9	64	2.2	15
Colorectal cancer	203	2.7	10	95	3.3	7



The Story of Heart Disease

At each of the focus group sessions we asked a small number of open questions and the responses were captured in words and pictures.

To get a better understanding of living with heart disease we had a conversation with members of the Cardiac Support Group. The group is run by volunteers, who have themselves had heart surgery and provide patients and relatives or carers with practical support and information from their own experiences.

We have included contact details for all groups at the back of this report.



HELPS SUPPORT
it's a wonderful thing

HEALTHCARE WAS...
I HAVE WAITED FOR 6 MONTHS
GP WAS BRILLIANT!
MY GP IS BRILLIANT!
THE PROBLEM IS BEFORE and HOSPITAL OPERATION SUPPORT GROUP

MY EXPERIENCE
I HAVE ALWAYS BEEN FIT
IT WAS A SHOCK
WHY ME?
NOW I HAVE Limitations
NOW "I CAN'T OVERDO THINGS"
... BEING ALWAYS TIRED
IT HAS BEEN A LONG JOURNEY
YOU DO THIS... OR YOU MAY NOT SEE TOMORROW
I HAD THOUGHT IT WAS OLD AGE
A LOT OF TABLETS
WHY ME?
NO ONE IS DOWN HERE... WE ARE ALL UP HERE
...THOUGHT I ONLY HAD A BROKEN FOOT
IT'S A LIFE CHANGER
WE ALL HAD THE SAME PROBLEM
I DON'T KNOW WHAT "NORMAL" IS ANYMORE
... MY FATHER DIED OF A HEART ATTACK
I WANT THIS SORTED AS SOON AS POSSIBLE ASAP
CAN I GO ON HOLIDAY?
LONG-TIME WAITING
LACK OF COMMUNICATION
REHAB AFTER LOOKING FOR CARE
A DIFFERENT AREA CAN MAKE A HUGE DIFFERENCE
MY EVERYDAY
I AM MAKING UP FOR LOST TIME
I AM NOT DIFFERENT FROM ANYONE ELSE
PEOPLE ARE MORE IMPORTANT THAN THINGS!
A DIFFERENT VIEW POINT
WE NEED A LOT OF DETERMINATION
WE DON'T WANT TO BE A BURDEN
I AM ALRIGHT!
WE ARE ALL INCREDIBLY LUCKY
WE USUALLY LIVE IN GENERAL
EMERGENCY? Call 999
DO YOU NEED ANY HELP?
DON'T BE AFRAID TO ASK "IT'S NOT TRIVIAL"
COMMUNICATION!
CATCH!
HOW ARE WE GOING TO BE IN THE FUTURE?
WE NEED MORE COMMUNICATION!
I GET A LOT OF SATISFACTION FROM A SMILE!
YOU NEED SOMEONE TO TALK TO...
IT IS REALLY HARD TO DETECT
MUM YOU LOOK SO WELL!
YOU CAN'T SUFFER IN SILENCE
I AM NOT DIFFERENT FROM ANYONE ELSE
I AM MAKING UP FOR LOST TIME
I AM ALRIGHT!
WE DON'T WANT TO BE A BURDEN
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WE NEED MORE COMMUNICATION!

HULL CITY COUNCIL HULL CARDIAC SUPPORT GROUP ❤️

CREATIVE CONNECTION

What is it like living with a heart condition?

People commented on the wide variety of heart conditions and symptoms that they were living with and operations they had undergone, from bypasses and valve replacements to living with heart failure, heart murmurs, even the shock of finding out they had an undiagnosed heart condition from early childhood or birth.

"I kept going for tests and was told you need a new aortic valve. I was so low; I just couldn't cope at home. In the end they said, you've got a year if you don't have this operation, so that concentrates your mind"

"I've had a heart murmur from being a child. I couldn't ride a bike, I couldn't play out. I was treated as an invalid. But that was 64 years ago. I would attend hospital twice a year for check-ups. I had an aortic valve operation 32 years ago and am still going strong. Cardiology has improved so much and things they can do now are unbelievable"

"There's many people walking around that don't know they've got anything wrong with their heart and suddenly they're told and it's a big shock"

"I'd been fit all my life, played sport right up to 55, cricket, football, was active walking. I went to the doctor for one of these health checks and I had no symptoms whatsoever. The doctor listened to me and he said; 'I think I can hear a murmur'. After numerous tests he said I needed a new aortic valve"

Many described their diagnosis as being a 'wake-up call' to change their lifestyle and also the frustration of the limitations some diagnoses impose.

"I didn't realise exactly how bad I was at the time, then all of a sudden, you need this operation, otherwise you're not going to see tomorrow. I'm extremely grateful for everybody that's contributed to my future"

"I get very disappointed that I can't do all the things that I used to. You know, you're a bit restricted having to sit and rest, it's very boring"

"You don't want to be a burden on your children. You plod on"

"You do have to be determined, you really do, it's no point looking at the downside"

Others were surprised that heart disease was not the 'life sentence' they initially assumed it to be.

"People think it's the end of the world, but it isn't in this day and age"

"You can live a long time with heart failure now, with the right medication"

"I'm grateful for all these years that I've been able to have a normal life since the operation"

"I had a triple heart bypass in 1995 and at the time, when I was told, I was thinking that'll be my lot. I really thought that I'd had it before the operation"

What helps you live the best life you can with your heart condition?

The things that keep people going are friends, family, faith and sheer determination. The support of other group members was seen as invaluable, especially for those living alone.

“Determination. You won’t let it beat you”

“It’s a lot harder when you’re on your own. Some of the group will ring me up and say, how are you? I always say, I’m fine, I’m plodding on but there’s days when I don’t want to plod on”

“Support is a wonderful thing, no question about it”

What would help improve life for people with a heart condition in the future?

People felt that better communication and follow-ups as well more time and resources would improve their lives.

“The GPs should be available to listen more”

“Lack of communication is the big problem. The GP doesn’t talk to the hospital as they don’t have the same system. It depends where you live as to what follow-up you get. Some areas do rehabilitation and some don’t, it’s just a mish-mash”

“I never get called in to see the GP. They’re supposed to call me in once a year, at least, but I have to make the appointment myself, as they never do”

“It’s a bit embarrassing calling an ambulance. You feel guilty for a start because they’re that busy”

What’s good about coming to this group?

The support group is cherished for its shared sense of camaraderie in dealing with the same issues, a place that gives everyone a renewed sense of optimism, a different perspective on life and somewhere they can share a laugh.

“You need someone to talk to and sometimes you don’t want to worry your family. It’s difficult sometimes but you can talk to a stranger because you can tell them everything”

“We’ve all had the same problems and that creates camaraderie”

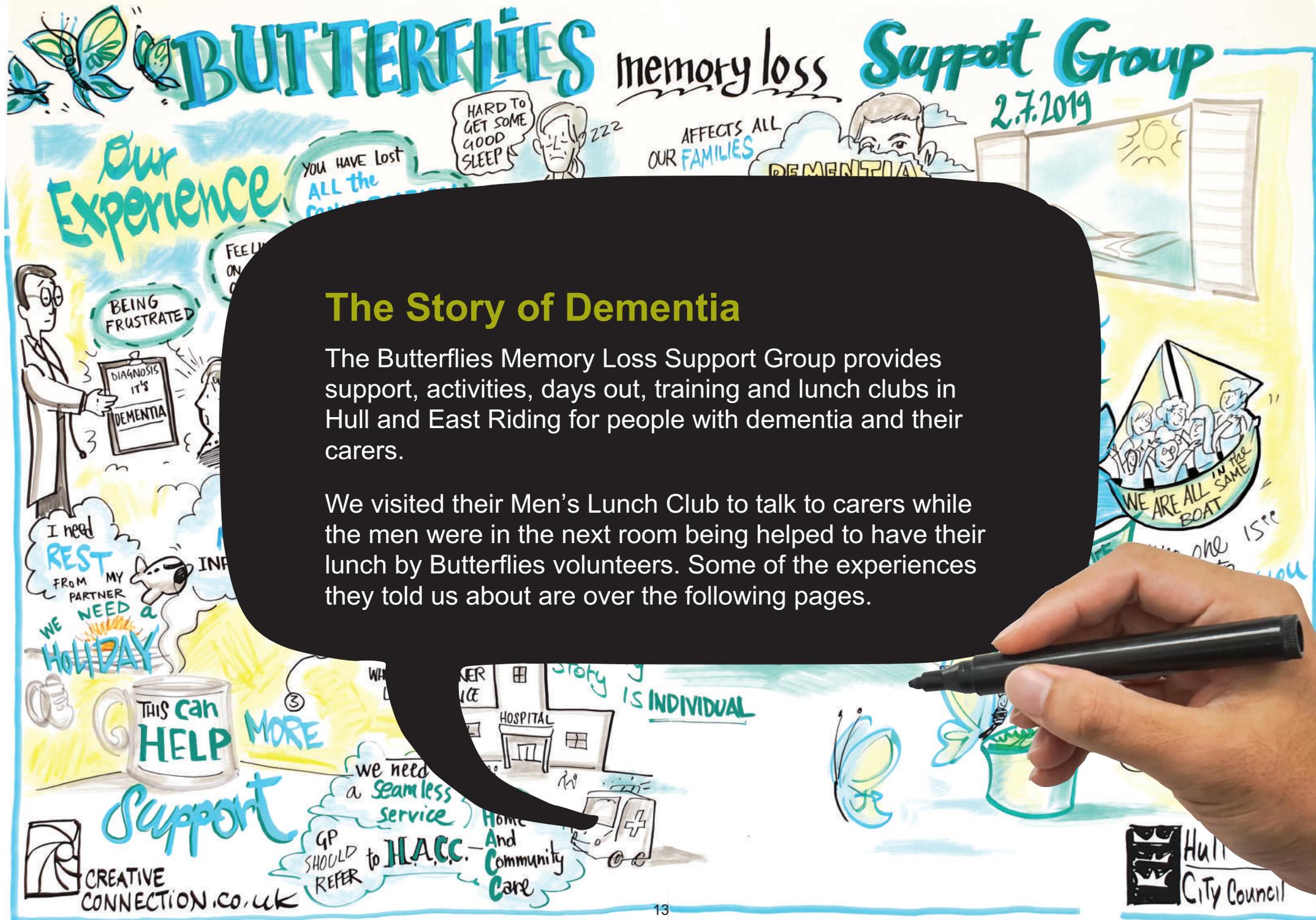
“One of the biggest things I get from this group is that no-one is down. Everybody is up and it is so uplifting to come to a group like this. It pushes you on, it really does”

“The group is a life-changer, literally for everybody, but it’s a life changer for the better.”

“You look at life in a different way and you make the most of it. We’re all incredibly lucky”

“You get a different viewpoint on your life and you realise that people are more important than things”

“We all take the mickey out of each other”



The Story of Dementia

The Butterflies Memory Loss Support Group provides support, activities, days out, training and lunch clubs in Hull and East Riding for people with dementia and their carers.

We visited their Men's Lunch Club to talk to carers while the men were in the next room being helped to have their lunch by Butterflies volunteers. Some of the experiences they told us about are over the following pages.



BUTTERFLIES

memory loss

Support Group

2.7.2019

Our Experience

YOU HAVE LOST ALL THE CONVERSATION

HARD TO GET SOME GOOD SLEEP

AFFECTS ALL OUR FAMILIES

DEMENTIA



IT'S DIFFICULT WHEN PEOPLE STARE

THOSE AFFECTED ARE NOT AWARE

I MUST BE ALRIGHT

I am a Dementia CARER

BEING FRUSTRATED

FEELING ON YOUR OWN



Feeling ANGRY INSIDE

THERE IS SO MUCH TO DO

Loneliness

Loss of Intimacy

Isolation



"AND WHAT NOW?"

ARE YOU THE CARER or the DISABLED?

I AM BOTH



I need REST FROM MY PARTNER

WE NEED MORE INFORMATION

step by step

CHALLENGES

every story IS INDIVIDUAL

WE NEED a HOLIDAY



WE ARE ALL IN THE SAME BOAT

"no one is going to judge you"

GROUP

RELIEF

MOST OF MY SUPPORT about what should I do is coming from this GROUP

LACK OF SUPPORT WHEN MY PARTNER LOSES BALANCE



we need a seamless service

Home And Community Care

GP SHOULD REFER to H.A.C.C.



Support

CREATIVE CONNECTION.CO.UK



What is it like, caring for someone with dementia?

Caring for a loved one with dementia can be relentless, lonely and frustrating.

“Well, it’s 24-hours a day. Loneliness is one of the biggest things, you know, especially if you don’t have any help. It’s just you and your partner”

“Even with family support you still have that feeling of being on your own because they’re not there 24-hours”

Carers explained that the relationship they had enjoyed before, as a couple, gradually goes and the loss of everyday conversations can be the hardest aspect to adjust to.

“You’ve nobody that you can talk with anymore, not as a couple. You’ve lost all that conversation”

“You’ve lost what you had as a married couple”

“Intimacy: that’s all gone”

People can never be fully prepared for the shock of the diagnosis coupled with the lack of immediate advice, information and support. Helping with this is the main reason Butterflies was set up.

“It’s the shock of the diagnosis. My husband was only in his 50s and he’s only just 60 now; it’s the shock of the complete change in his personality”

“When we was first diagnosed they just said ‘oh yeah, it’s start of dementia’ and that was it. We walked out the door and they never said ‘you can do this, do that, go there’. There’s no back up”

“You should have advice right from day one, but you don’t get it. Nobody tells you anything”

“It would’ve been nice if there’d been someone stood behind us and said ‘right, now you come with me and I’ll tell you what to do’, so you know what to do and what to expect”

“You get your diagnosis and that’s it”

How does living with someone with dementia make you feel?

The subsequent, and often devastating, changes in a loved one’s character and personality can have a negative impact on the carer’s own wellbeing, often making them feel angry, depressed and frustrated, not least because future hopes and plans often have to be erased. Extended families can also be adversely affected, as they have to adapt to new family dynamics.

“I feel angry and depressed. I’m on anti-depressants”

“I’m still depressed over it because he gets violent my husband. That’s why they put him in the care home because he attacked me; he smashed my arm in three places”

“It affects your family. My daughter’s had to come to terms with her dad being different”

“I sometimes feel angry, but angry inside, you know. All the plans that you’ve got for when you leave work, you’re gonna do this, you’re gonna do that, it’s all gone. All gone”

What's the one thing that would give you better quality of life in terms of caring for someone with dementia?

Carers want more information at the point of diagnosis, respite care and somewhere to go on holiday as a group with others.

"It would be nice if some people could set up a little place, say in Hornsea or somewhere, where you could go on holiday for a few days together. You know, a set time out from home with other people that's got husbands, wives with dementia, at least you've got some talking you can do, as well as be with your loved one and take them out"

There is a common frustration about long waiting lists for appointments for things like medication reviews.

"I got a phone call in January to say they'd had the referral and would send an appointment. It was May before I got in"

What does this support group do for you?

Whilst the men with a dementia diagnosis are helped by volunteers to have their lunch, the carers group offers a rare chance to be with people who really understand the daily struggles, share the same frustrations and have the same sense of humour. Knowing that experiences shared will be kept confidential makes it a safe space, non-judgemental place for members to speak openly.

"This club is a God-send, it's a lifeline"

"We all know how each other feels, whereas nobody else does"

"We can enjoy having a good moan and being able to laugh about it!"

"You know nobody's going to blame you or judge you. Nobody's even gonna take it out of this room. What you share in here, stays in here"

What is the impact on your everyday lives?

Being out in public can be tricky; the behaviour of the cared for person can be challenging or embarrassing but public awareness is growing and the dementia badges, which identify the wearer as either a carer for someone with dementia, or a person who has the condition, have been a great help.

"We've all got a badge. It's like a pin and it says 'I've got dementia, please be patient' It can make such a difference"

"I'll wear it (the badge) under a collar and sometimes if things are going a little bit wrong and somebody comes across and says 'are you alright?' then I'll flip the collar and it just says 'I'm a dementia carer' and then you don't have to explain anything"

The constant responsibility of the caring role means that getting proper rest, sleep and respite care can be really difficult.

"I find it difficult to get some rest, to get quality sleep, because he'll wander at night. It's very difficult to care all day when your energy's gone"

"None of us want our partners to go into homes but sometimes respite care needs to be more available"

"I've rang the social services and said that I was struggling, I'm shattered and all I got was an envelope full of leaflets. I just cried"

"You're literally on your own because your partner has got dementia, you need a respite, but nothing is available for anybody"

Having a break or a holiday can make the world of difference to carers, as can integrated care that properly addresses all health and social care needs from one place.

"I've just been away on a week's holiday and it's just done me the world of good, getting one week away from it all."

"I was lucky really because I was able to go abroad, on my own, twice and what a difference it makes"

"We went to the Jean Bishop Centre and we got absolutely loads of help from there. We got all the things that he should've got years ago, like a commode for downstairs"



The Hull Picture

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, concentration, problem solving and language; problems that may become severe enough to impact negatively on everyday life. These changes are caused by a variety of brain diseases, the most common being Alzheimer's. While the risk of dementia increases with age, it is not an inevitable part of the normal aging process.

Dementia (classified as either the underlying cause of death or contributory cause) was the second most common cause of death in all age groups in Hull in 2015-17 accounting for 9.9 per cent of all deaths. The main risk factor for dementia is age, with the risk of developing Alzheimer's disease or dementia doubling every five years from the age of 65. Women are more likely than men to develop it and the risk is

higher among South Asians than it is among white Europeans. Our understanding of the condition has improved with advances in technology, so we know a number of genetic factors are associated with the condition, with around 20 genes increasing the risk of developing dementia.

In addition to genetic risk factors, there are also other risk factors that could potentially be reduced through changes in individual, community and population behaviours. A number of these risk factors apply also to cardiovascular disease, such as physical inactivity, smoking, poor diet and excessive alcohol consumption. A key message is that what is good for the heart is good for the head. Other conditions, such as Type 2 Diabetes, high blood pressure, high cholesterol and obesity are associated with an increased risk of developing dementia, so ensuring optimal management of these conditions is crucial to reduce the risk.

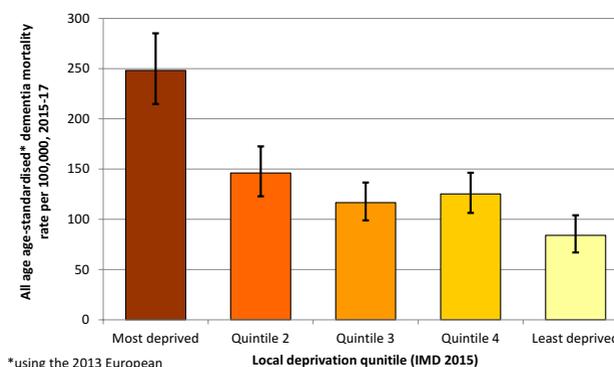
Director of Public Health Annual Report 2019

The overwhelming majority (95.6 per cent) of patients diagnosed with dementia in Hull are aged 65 and over; the prevalence among people aged over 65 in Hull in 2018 was 4.8 per cent, which is higher than both England (4.3 per cent) and the Yorkshire and Humber region (4.5 per cent). This means that there are around 2,300 individuals and families living in Hull with a diagnosis of dementia, and experiencing the challenges associated with the condition. (The Alzheimer’s Society puts the total number of people over 65 living with dementia in Hull at around 2,800, because an estimated 15 per cent of people with the disease do not yet have a diagnosis.)

The prevalence of dementia in Hull among those aged 65+ years is 10 per cent higher than for England and six per cent higher than for the Yorkshire and Humber region. However, emergency admissions for dementia in Hull among those aged over 65 (5,255 per 100,000 in 2017/18) were 46 per cent and 35 per cent higher respectively than for England and the Yorkshire and Humber region. This raises questions around whether individuals with dementia living in Hull experience a greater level of multi-morbidity than individuals with the condition elsewhere, or whether there are gaps in services to support these individuals.

As with cardiovascular disease, which shares risk factors with dementia, there is a stark trend in terms of socioeconomic status, with the most deprived populations in the city experiencing a disproportionate level of mortality due to dementia than less deprived populations.

Figure 5: All age directly standardised dementia mortality rates 2015-17 by local deprivation fifths

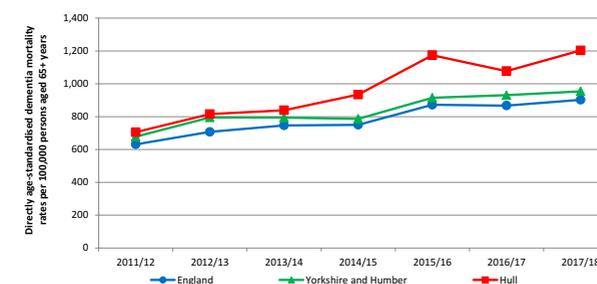


*using the 2013 European Standard Population

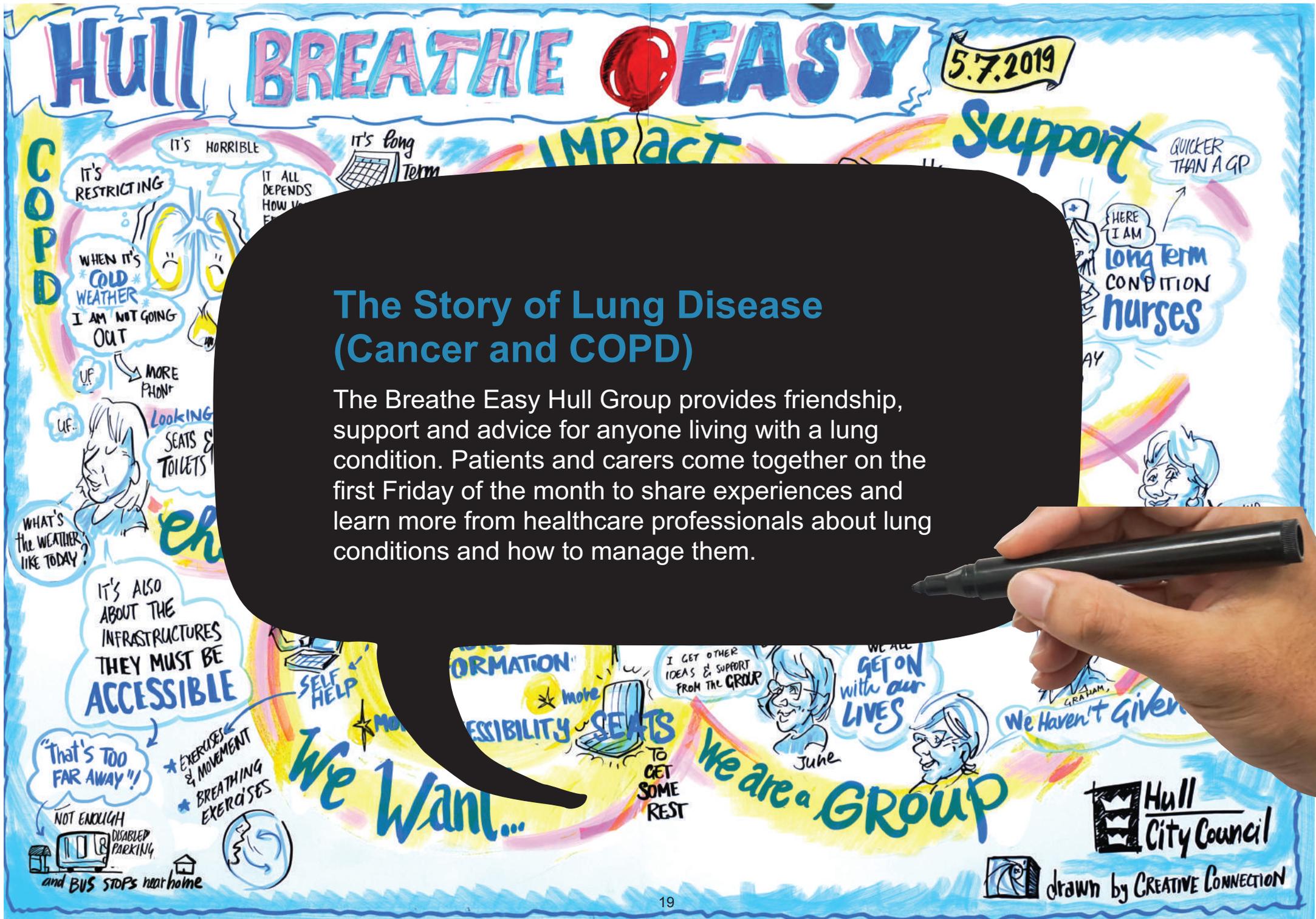
Among people aged over 65, the age-standardised dementia mortality rate in Hull in 2017/18 was 1,203 per 100,000 persons, one third higher than for England and one quarter higher than for the Yorkshire and Humber region. Rates in Hull increased between 2011/12 and 2017/18 by 71 per cent, much higher than the 43 per cent and 40 per cent increases seen respectively for England and the Yorkshire and Humber region. This substantial

difference may be a result of some work undertaken in the city to improve the diagnosis of dementia which occurred in the lead-in period to the Jean Bishop Integrated Care Centre opening, or could be related to other factors including changes in clinical practice. It is something that the Public Health Intelligence team will be looking into in more detail.

Figure 6: Trends in 65+ directly standardised dementia mortality rates per 100,000 persons aged 65+ years



*using the 2013 European Standard Population



The Story of Lung Disease (Cancer and COPD)

The Breathe Easy Hull Group provides friendship, support and advice for anyone living with a lung condition. Patients and carers come together on the first Friday of the month to share experiences and learn more from healthcare professionals about lung conditions and how to manage them.

HULL BREATHE EASY

5.7.2019

Impact

Support

COPD

IT'S HORRIBLE
IT'S RESTRICTING
WHEN IT'S COLD WEATHER I AM NOT GOING OUT
IT ALL DEPENDS HOW YOU ARE FEELING ON THE DAY
Asthma

IT'S LONG TERM

you lose a lot of FRIENDS

IT'S HARD TO TALK

NOT FOR ME!
I CHOSE TO GET IN A WHEEL CHAIR

we like VISITORS

QUICKER THAN A GP

HERE I AM
long term CONDITION nurses

EVERYDAY HELP

challenges

WHAT'S THE WEATHER LIKE TODAY?
Looking for SEATS & TOILETS
"ALL YOU NEED IS A HOOK TO PUT YOUR CLOTHES ON"

GP IS NOT ENOUGH

COULD YOU COME BACK IN THE AFTERNOON?
antibiotics
WHAT?

WE NEED IT FOR SUPPLIES FOR MEDICATION at the RIGHT TIME!

MORE INFORMATION

MORE ACCESSIBILITY SEATS TO GET SOME REST

We Want...

We are a GROUP

IT'S ALSO ABOUT THE INFRASTRUCTURES THEY MUST BE ACCESSIBLE

there is an APP...
SELF HELP

"That's TOO FAR AWAY!"

EXERCISES & MOVEMENT
BREATHING EXERCISES

NOT ENOUGH DISABLED PARKING and BUS STOPS near home

WE CAN MEET OTHERS WITH THE SAME CONDITION

YOU GET MORE INFORMATION about COPD

I AM ALSO HERE FOR THE COFFEE... AND FRIENDS

We Haven't given up!!!

WE ALL GET ON with our LIVES

I GET OTHER IDEAS & SUPPORT FROM THE GROUP

Hull City Council

drawn by CREATIVE CONNECTION

What is it like living with a lung condition?

Focus group participants told us that, much like other long-term conditions, living with a lung condition can make day-to-day activities harder. Not only that, the weather can have a huge impact.

“It’s horrible every day not being able to breathe, gasping all the time”

“It stops you doing everyday chores.

Everyday chores are a task, not a pleasure as they used to be”

“The cold weather really affects you, you tend to hibernate so you don’t get a chest infection, but its lonely then, isn’t it?”

“You lose a lot of friends, you definitely do. You lose ones that have still got the ability to walk at speed”

What’s the most challenging thing about living with the condition?

The group explains that the hardest aspects of not being able to breathe very well include the loss of activity, the inability to walk very far, walk upstairs or up even up slopes. It can be hard to find places to rest when out and about, or to find disabled parking places near to where you want to go. Admitting that you need help from friends and family is hard to come to terms with.

“Not being able to do any physical exercise, walking upstairs”

“Hills, even shopping centres have all got slopes and you can’t get up them”

“Even having visitors can make you get breathless”

“I can only go so far before I need to sit down. There’s only three seats the length of Whitefriargate”

“Its things like downstairs toilets as well. There’s a lot of problems we’ve had to think about. We have to think about where we’re going”

“It is hard to accept that you need somebody to help you”

People really felt the loss of the specialist nurses from the Long Term Conditions team, who used to do home visits.

“Long-term conditions team; they’re the ones that I miss. They were fabulous; they were used to dealing with people with bad lungs, you could give them a ring about your medication”

“They would come every day until you were better. When they were taken away, that was really bad”

Having a lung condition is often an ‘invisible illness’ which can make life harder, especially when it comes to communication.

“Because you look alright, people don’t think you’re ill and don’t give you enough time to talk”

“I had the hairdresser on the phone the other day saying, ‘what do you want, hurry up’ and I couldn’t speak”



Getting GP appointments, having access to the same GP or being given 'just in case' medication can be very tricky.

"If you suddenly dip, you obviously need the GP for some medication and it's getting through to the doctors with so much queuing on the phone"

"I always have what's called rescue; stand-by antibiotics and steroids. I wouldn't have to go straight to the GP"

"Not all GPs like giving stand-by, my GP won't give it"

"I've had 'just in case drugs' for years, it is good that, but he's took them away now"

"When you go to see a doctor, you get a different doctor every time and then you've got to go through the same rigmarole of what you've got. To me you should have your named doctor"

What would help improve life for people living with a lung condition?

Some people had taken part in a trial using an app called My COPD, which had really helped them manage their condition.

"The app is really good. You can register your medicines what you take every day. You do an exercise thing on it and you can get information on everything - what the pollen's like, what the weather's like. It's really interesting and I think it would help anyone with this condition."

"You can do it in your own time, you get ten exercises"

What is good about the Breathe Easy Group?

People really value the information-sharing, the friendship and the positivity that the group offers.

"Sharing things with each other helps. You get more information by coming here than anything"

"You learn more off other people that suffer the same"

"I'm fairly new to the group and I come here for the company"

"We're all quite positive here, because we all get on with our lives, we're living with it. We haven't given up and sat in an armchair!"





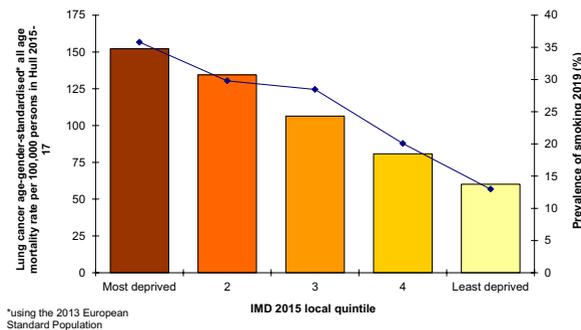
The Hull Picture

Lung cancer was the third most common cause of death in Hull (2015-17) and the most common cause of death in people under the age of 75. Men are more likely to develop lung cancer than women.

Almost four in five cases of lung cancer are preventable, so potentially around 170 cases of lung cancer a year in Hull could be prevented. In Hull, the rate of lung cancer in men is 72 per cent higher than the England rate, but for women the Hull rate is 82 per cent higher than England.

The main preventable risk factor for lung cancer (approximately 72 per cent of cases) is smoking. The remainder are thought to be caused by workplace exposures, air pollution and ionising radiation.

Figure 7: Deprivation, smoking and lung cancer mortality (all age)



Nationally, there is a steady reduction in lung cancer deaths in men and women, although the reduction in women is substantially slower. In Hull, we have also seen a substantial reduction in lung cancer deaths in men, but lung cancer deaths in women appear to have been slowly rising for the last ten years, though the data suggests that this rise has now levelled out. This is reflected in our

local smoking rates, with smoking in men dropping but smoking in women remaining static or increasing.

Hull experiences almost twice as many people dying due to lung cancer under the age of 75 years (62.0 per 100,000 individuals) than England does (31.1 per 100,000 individuals).

Within the city, there are also marked differences between geographical areas, and between men and women. North Hull experiences the highest death rate due to lung cancer (72.5 per 100,000 individuals), but this appears to be driven by a higher death rate in men (87.0 per 100,000 males) compared to women (60.0 per 100,000 females). Women in West Hull experience the highest death rate due to lung cancer (66.0 per 100,000 females) whereas the men in West Hull experience the lowest in the city (57.2 per 100,000 males).

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We can see that deaths due to lung cancer follow the socioeconomic gradient, being higher in the most deprived communities and decreasing as deprivation decreases.

A key factor in the high death rate is the problem of late diagnosis. Of the lung cancers that are diagnosed in Hull citizens, the majority are diagnosed at more advanced stages. Like all types of cancer, the earlier people are screened or symptoms are checked, the sooner cancers can be diagnosed and treated, and the better the outcome for the individual.

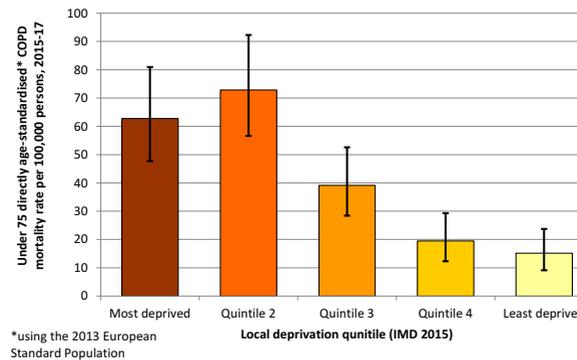
Chronic Obstructive Pulmonary Disease (COPD) is a largely preventable respiratory condition; around 80 per cent of COPD deaths are estimated to be caused by smoking. For Hull, this would mean that of the 602 people that died from COPD in 2015-17, around 480 died because of smoking; this would be equivalent to three people dying from COPD every week in Hull who only did so because they had smoked cigarettes/tobacco.

In 2017-18 there were approximately 8,000 individuals diagnosed with COPD registered with Hull GPs; this would give a prevalence of 2.7 per cent compared to the national prevalence of 1.8 per cent. The prevalence in the most affluent practices was almost half that of the least affluent; this is not surprising given the smoking rates in some of the more deprived communities in the city.

COPD was the fourth most common cause of death of all ages and the third most common

cause of premature death. In terms of relative deprivation, premature deaths due to COPD are lowest in the least deprived fifth, but there is little difference between the most deprived two fifths.

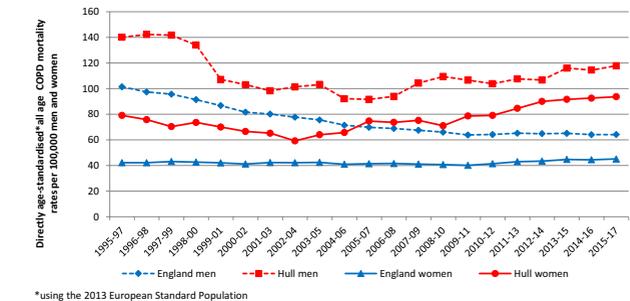
Figure 8: Under 75 directly standardised COPD mortality rates 2015-17 by local deprivation fifths



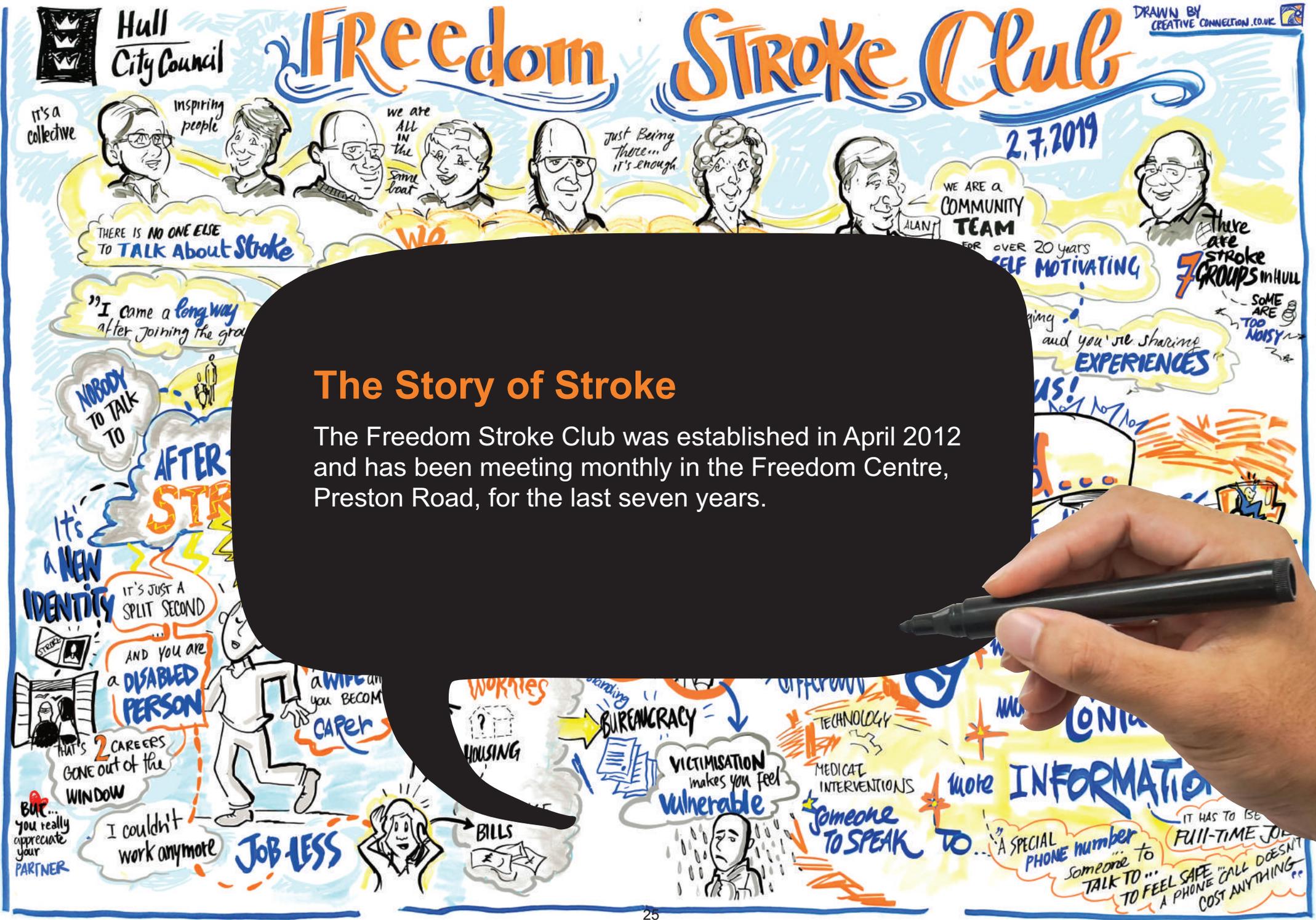
Most deaths due to COPD occur in those ages over 75 years (64 per cent) as COPD is a condition that individuals can live with for a substantial period of time. The rate of deaths due to COPD in men over the period 1995-97 to 2015-17 has decreased locally and nationally, but the national reduction of 37 per cent is more than twice the reduction seen in Hull, of 16 per cent. In 2015-17, the COPD death rate among men in Hull (118 per 100,000 men) was almost double the rate for England (64 per 100,000 men). Despite decreasing in Hull overall since 1995, the COPD death rate among men has increased by 29 per cent since 2005-07.

Among women of all ages, deaths due to COPD increased locally and nationally between 1995-97 and 2015-17; the increase in Hull (18.5 per cent) was almost three times that seen nationally (6.9 per cent). The rate for England was relatively flat until 2009-11, since when it has increased in five out of six years. In Hull however, COPD all age mortality among women increased between 2002-04 and 2005-07, and again for most years since 2008-10, with the rate peaking in 2015-17 at 94 deaths per 100,000 women; this is more than double the rate for England (45 deaths per 100,000 women).

Figure 9: All age directly-standardised COPD mortality rates, Hull and England trends



Like lung cancer, death due to COPD is higher in our most deprived communities, and lower in our least deprived. This follows the smoking rates in terms of deprivation.



The Story of Stroke

The Freedom Stroke Club was established in April 2012 and has been meeting monthly in the Freedom Centre, Preston Road, for the last seven years.





Hull City Council

Freedom STROKE Club

DRAWN BY CREATIVE CONNECTION.CO.UK

2.7.2019

It's a collective



Inspiring people



We are ALL in the same boat



Just being there... it's enough



ALAN

WE ARE A COMMUNITY TEAM

FOR OVER 20 years IT'S SELF MOTIVATING



There are 7 STROKE GROUPS in HULL

SOME ARE TOO NOISY

THERE IS NO ONE ELSE TO TALK ABOUT STROKE

We are a Group

From 15 APRIL 2012

we need SUPPORT

"you are bringing IDEAS back and you're sharing EXPERIENCES"

"I came a long way after joining the group"

WE UNDERSTAND WHAT WE BOTH are going through

...so join US!

NOBODY TO TALK TO

Long ago... after you come HOME from HOSPITAL you are on your own NOW THERE IS MORE SUPPORT



COMMUNICATION IT'S GIVING YOU SELF-WORTH

AFTER the STROKE

Every story IS INDIVIDUAL

on the road to Recovery

We need...

MORE AWARENESS with employers TRANSPORT FOR WHEEL CHAIRS

more TIME

more CONTACT

more INFORMATION

It's a NEW IDENTITY

IT'S JUST A SPLIT SECOND

AND you are a DISABLED PERSON

IT'S NOT JUST PHYSICAL

emotional SOCIAL psychological

You are not a WIFE anymore... you BECOME a CARER

WORK WORRIES HOUSING ? MORTGAGE ?

BUREAUCRACY

VICTIMISATION makes you feel vulnerable

every body IS different



THAT'S 2 CAREERS GONE out of the WINDOW

But... you really appreciate your PARTNER

I couldn't work anymore

JOB LESS



BILLS

someone TO SPEAK TO

A SPECIAL PHONE number someone to TALK TO... TO FEEL SAFE "CALL DOESN'T A PHONE COST ANYTHING"

IT HAS TO BE A FULL-TIME JOB

What is good about coming to Freedom Stroke Club?

Stroke survivors and carers told us how much they really benefit from being able to share with others 'in the same boat' who really understand what life is like after a stroke.

"There's no one to talk to about stroke and the problems you're having so it's nice to talk to people that understand"

"I went along to the club and everything just fell into place"

"Sometimes you can start a group and it's hard going but this one was easy. It's self-motivating. You're sharing experiences with other people"

The socialising is a big bonus and being able to see recovery and progress in others gives people hope, encouragement and goals to strive for.

"His face on the day we go to the club; it's a picture; he can't get there fast enough. He's come on leaps and bounds"

What's life like, as a 'stroke survivor' or carer?

The biggest challenge is that stroke is so sudden and can be life changing in so many ways. A relationship changes overnight from the partnership of a couple to disabled person and carer. Just as disability is hard to come to terms with, the demands on the person in the caring role can be huge and hard to adapt to as well. Everyone affected must learn new skills to overcome new challenges.

"It's not just physical, it's emotional, it's psychological, it's cognitive; it's all sorts"

"I do his full time care, all day and every day"

"It's life changing because people go from having careers to overnight being a full time carer without any planning"

"You're not a wife, you become a carer and you feel as though you don't have much of a life yourself"

"I couldn't get his wheelchair in the taxi. So I said that's it, I'm learning to drive. So at 50 I learnt to drive"

Coming to the club and filling time with other things like volunteering can be a life-saver.

"Being able to volunteer has been fantastic"



How has stroke impacted on your everyday life?

The impact on work and finances can be huge. Not being able to continue the role of bread winner can diminish confidence and self-worth. There is a need for more help and awareness from employers.

"It's the silly things that you don't even think about. I had insurances that if I'd died my house would've been paid off, but I didn't have critical life insurance. If you've always worked you don't know how to apply for benefits, or look at housing situations"

"There should be more awareness with employers and that's a big thing"

"With stroke everyone is different, disabled in different ways and to different levels so there's no book on it"

"What helped me was getting involved in the group because I lost my job and it's given me self-worth"

What would help improve life for people after having a stroke?

Some of the things that would make life better, would be more community stroke nurses, a helpline or just someone to talk to, access to community transport, more help with medication and speech problems.

"Even after 21 years I would still like to have someone I could go to and say is this normal or am I going crazy?"

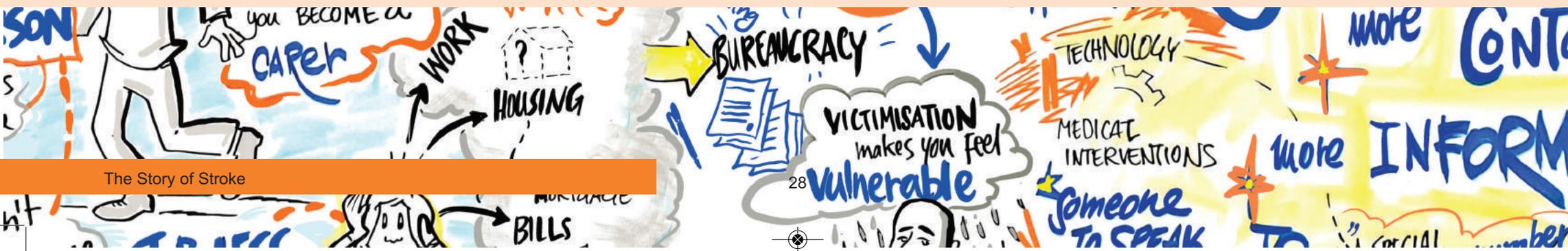
"So I'm on 32 tablets a day but no one ever explains the medication as there's no communication now"

"I just want another human being to make sure I'm safe as I don't have a carer or anything. Just somebody there I could ring up and talk to occasionally"

"Community stroke nurses used to come round and support the carer as well, which doesn't happen anymore"

"It's difficult trying to get transport that will take somebody with a wheelchair so going for a day out is difficult"

"We could have more stroke survivors access the Freedom Stroke Group, but for lack of suitable wheelchair accessible vehicles and the lack of a hoist to allow visitors to access the toilet"



The Hull Picture

Stroke is a condition of the cardiovascular system; the main risk factor is having high blood pressure. A stroke occurs when there is either a bleed into the brain, or where an area of the brain is starved of blood due to a clot or complete narrowing of the blood vessels. An irregularity of the heartbeat, called Atrial Fibrillation, increases the chance of a stroke due to a clot. These can be prevented by identifying the irregularity of the pulse rate and treating the individual with an anticoagulant to reduce the risk of a clot forming.

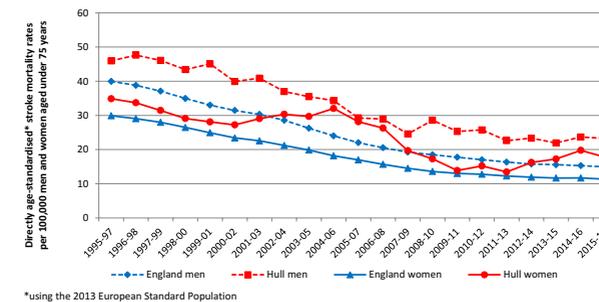
The consequences of stroke can vary enormously from symptoms that are almost imperceptible, to death. The impact of stroke on individuals, families and communities is huge; this can be through bereavement, or through the individual having high levels of complex care needs.

There are almost 5,000 individuals registered with Hull GPs diagnosed with having had a stroke; obviously these are the individuals who survived their stroke.

Stroke was the fifth most common cause of death and the sixth most common cause of premature death in Hull during the period 2015-17. The rate of premature death has decreased substantially over the period 1995-97 to 2015-17 although the improvements remained slower than those experienced nationally; both men (23 per 100,000 men) and women (18 per 100,000 women) in Hull experience a 50 per cent higher mortality rate than the national rate (15 per 100,000 men and 11 per 100,000 women).

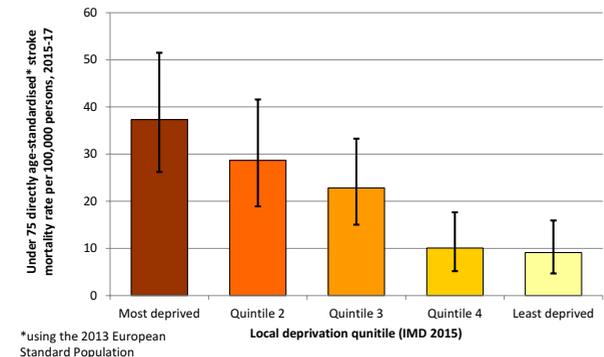
In Hull, death rates due to stroke among men have remained stable since 2011-13, but for women the rates have increased; the rates for England have continued to decrease over this period, albeit at a slower rate than seen in earlier years.

Figure 10: Trends in under 75 directly standardised stroke mortality rates



There were substantial differences in premature death due to stroke when the population is considered in terms of deprivation. The rate among people living in the most deprived areas of Hull (37 per 100,000) was four times higher than among those living in the least deprived areas of the city (nine per 100,000).

Figure 11: Under 75 directly standardised stroke mortality rates 2015-17 by local deprivation fifths



*using the 2013 European Standard Population

Whilst this section has considered premature death due to stroke, more than three-quarters (77 per cent) of deaths due to stroke occur in individuals aged 75 years and over. Although the rates are higher in this age group, the trends in terms of deprivation and gender differences remain.

High blood pressure and an irregularity of the pulse (atrial fibrillation) are the main risk factors linked with stroke. There are some risk factors for high blood pressure which cannot be altered, although the majority can; actions that individuals can take to reduce their blood pressure include maintaining a healthy weight, regular exercise, reducing alcohol consumption, not smoking and reducing their salt intake. Some of these actions may also reduce the likelihood of developing atrial fibrillation, but should this develop, early diagnosis and treatment with anticoagulant medication (if appropriate) is also important to help reduce the risk of stroke.



Conclusion

“Life expectancy tells us a great deal about how we are doing as a society. It’s really urgent to ask what’s going on, what’s going wrong and what can we do about it?”

Sir Michael Marmot, 2019 ‘The Marmot review ten years on’ (2)

I set out my report this year with a focus on how we could use a population health framework to understand life expectancy and healthy life expectancy, reduce the burden of long term conditions and improve outcomes. I have used this framework for my conclusions and recommendations.

A Focus on Wider Determinants

All our decisions about how we address inequalities in life expectancy and healthy life expectancy should be informed by our data, evidence of best practice and from engagement with those who understand these issues the most: our local people.

Our data reminds us that in Hull the big killers are largely preventable conditions, and they are disproportionately impacting the most

disadvantaged groups and communities. After many years of progression we are seeing a stalling of improvement in life expectancy and healthy life expectancy. The causes are based in our life experiences, how we are born, grow, learn, live our lives, work and age. These experiences shape the choices we make. That’s why a population approach is crucial to turning the curve.

Social inequalities create inequalities in health. These inequalities are unjust, unfair and unnecessary. Everyone benefits from a more equal society, socially, economically and in terms of health and wellbeing outcomes.

In Hull we have made significant progress on economic growth, £3bn investment in our infrastructure, higher than national average growth in GDP, employment and housing. A successful UK City of Culture year and a recent successful Heritage Lottery Bid for our Maritime City project have led to a renewed pride in our ‘Place’. Yet, despite our best efforts we still have 30 per cent of children and 25 per cent of older people living in poverty, our children and young people are in too many cases not reaching their potential and our progress on reducing harm from preventable risk factors including tobacco, alcohol and drugs is too slow.

We know that economic growth doesn’t trickle down to those who need it the most and we know that we have to work together as a whole community to create a fairer more inclusive Hull.

Health Behaviours and Lifestyles

Our approach to supporting people to make healthier choices has had a significant impact. We are seeing good signs that our ambition for a smoke free generation by 2025 is taking hold. 92 per cent of our children and young people choose not to smoke, the number of women smoking in pregnancy has fallen significantly and our drug and alcohol service is seeing more people through to sustainable recovery. Our Towards An Active Hull strategy was launched this year, setting out how we will support 10,000 people who are currently inactive to become active, and our systems wide approach to tackling childhood obesity is moving into the next phase. Here we will be bold and ambitious in securing the step change needed to secure a healthier future for our children.

A renewed focus on preventing ill health and tackling health inequalities is central to the NHS Long Term Plan (3) and implementation framework. This has to be welcomed. Previously, prevention has not been seen as core business for health and social care services but rather as an add-on extra if resources allow. There are really positive signs that our new Primary Care Networks will work alongside partners and communities to step up their actions in refocussing resources towards prevention and early prevention.



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Integration of Health and Care Systems

Hull has a really strong story to tell about integration. We have a 'Place' approach with a focus on people and place outcomes and a thriving partnership across private, public and community sectors.

Hull City Council and CCG have an integrated financial plan of £640m and are making joint decisions about the health and social care services we buy and provide for children and young people, adults and older people.

The Integrated Care Centre (Jean Bishop Centre) was the first of its type in England. People living with frailty are now benefiting from a truly holistic approach where a range of clinical, social care and support services review the patient and create an integrated package of care and support. The outcomes speak for themselves; significant reduction in the need for emergency and hospital care and reductions in medicine costs. We are now expanding this service to include COPD, stroke and dementia.

The development of our Primary Care Networks gives us a real opportunity to ensure we have consistently high standards in terms of screening and evidenced based early intervention and

treatment, including self-care. NHS Health Checks and our Integrated Care System work will provide 'at scale' interventions to improve mental health, improve cancer outcomes and ensure modernised acute hospitals contribute to prevention and ongoing support.

Integrated technology has a big role to play in supporting people to remain active and independent and in ensuring we have timely information at our fingertips. Our partnerships with universities and local tech companies should be strengthened so we can go further, faster.

Our Communities

No one better understands the importance of population health, earlier intervention, early diagnosis and ongoing support than those living with a long term condition. In Hull, we are seeing many more people living with more than one long term condition impacting on their life expectancy, independence and quality of life. Our volunteer Patient Groups support people living with a long term condition for many years and provide advocacy, advice and support at crucial times. The overriding message we heard was that these groups provide essential support and reduce social isolation. Thank you to each and every one of you. You are amazing.

You told us that diagnosis is life changing; it affects every aspect of life, dignity, confidence, intimate relationships, work, income and social life. You eloquently described your emotions and the gaps in ongoing support from diagnosis to end of life. Your messages about communication at and beyond diagnosis remind us that if we get this right first time we can improve outcomes overall. You reminded us that for far too long NHS and social care have focused on treating ill health and now needs to prioritise resources and efforts towards prevention and early intervention, recovery and rehabilitation.

And finally, it's important to say that there are some significant issues outside of local government control. Government policy on housing, benefits, taxation and local government funding all have an impact on health inequalities. At the time of writing, Brexit uncertainty, the delay in the publication of the Green Paper for adult social care and the unprecedented level of uncertainty about local authority financial settlements, including funding for social care and public health, are undermining all our efforts to maximise prevention activity and outcomes. Whilst the landscape is complex, we are in charge of our future.

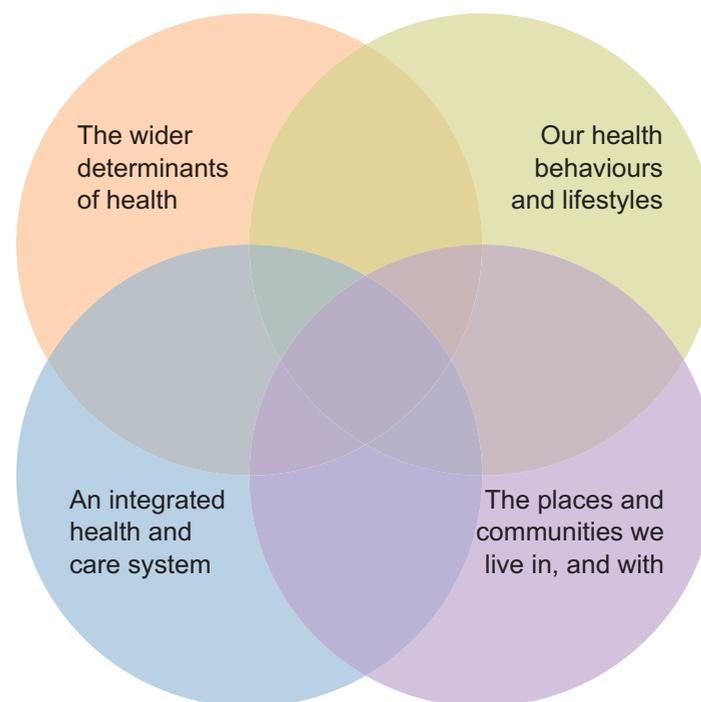
Areas for Action

System wide, upstream support is the key to reducing the risk of developing these devastating long term conditions that shorten lives and reduce the quality of life. Whilst the landscape is complex and challenging we have a collective responsibility to secure a healthier future for our city, our communities and our people.

Much of what is needed to make a positive impact is in our gift, and the Health and Wellbeing Board has a key responsibility to activate the partnerships across the city to deliver the following:

- Develop and ensure robust oversight of an updated health and wellbeing strategy with prevention at its core, making explicit commitments to improving health outcomes and addressing health inequalities
- Champion a renewed focus on health inequalities and provide strong oversight of the Fairness Commission to ensure all four pillars of population health are considered
- Actively work with the Place Board and Business Leadership Board to maximise efforts for co-production and shared leadership to ensure effective delivery of health and wellbeing priorities for the city.

In providing leadership, the Health and Wellbeing Board should consider how best to address the four pillars of population health and ensure that all work integrates commitments across these four pillars:



The Four Pillars of a Population Health System (Source: The King's Fund)

Pillar 1: Wider determinants of health

- Hull City Council and its partners continue to take action on social policies and strengthening of Place to provide better opportunities to live healthier lives
- With Economic partners, maximise the health opportunities in supporting the delivery our Local Industrial Strategy and City Plan.

Pillar 2: Health behaviours and lifestyles

- Ensure there is clear leadership for population health and that plans are in place for co-ordinated action

- Champion a renewed focus on reducing health inequalities in smoking rates between social groups in Hull with a view to see significant improvement by 2025
- Ensure engagement with communities is key in driving and informing health priorities and effectively support the voluntary, community and faith sector to facilitate its voice and influence as an equal partner.

Pillar 3: Integrated health and care systems

- Demonstrate intent to take prevention seriously by effectively utilising commissioning opportunities to target resources on prevention at neighbourhood, city level and across the wider integrated health and care system

- Actively support a renewed focus on health inequalities across the integrated health and care system utilising best evidence in terms of service development and design.

Pillar 4: Our communities

- Recognise the key role that support systems and groups play in enabling people and their families to manage health conditions and support both physical and mental health
- Ensure practical support is consistently provided by health, social care and Voluntary, Community and Social Enterprise (VCSE) services to help those support networks to run effectively and sustainably across our communities.



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References

- 1 Buck D, Baylis A et al. (November 2018) 'A vision for population health towards a healthier future', The King's Fund www.kingsfund.org.uk/publications/vision-population-health
- 2 Sir Michael Marmot (2019) 'The Marmot Review Ten Years On' <https://youtu.be/vp9wPDrMDRU>
- 3 NHS England (2019) 'NHS Long Term Plan' www.longtermplan.nhs.uk/

Acknowledgements

I would like to thank all those who contributed to my annual report either through writing, design or producing data and pictures (Sally Barlow, Karen Bell, Des Cooper, James Crick, Joy Dean, Robert Sheikh Iddenden, Tim Fielding, Iain Musgrave, Ali Patey, Hannah Scorer and Jen Walker).

In particular I am grateful to Francesco Tassi of CreativeConnection for the 'visual minutes' from the four Focus Groups.

A special thank you goes to all those patients, relatives and carers who kindly provided such rich insight and feedback into the focus group discussions.

A wealth of information on the health and wellbeing of Hull's residents can be found on our Public Health website at www.hullcc.gov.uk/pls/hullpublichealth

Support group contact details

All groups welcome new members of any age and background and encourage all those who would benefit from support to get in touch.

Hull Cardiac Support group – visit: www.cardiacsupportgroup-hull.co.uk
email info@cardiacsupportgroup-hull.co.uk

Butterflies Memory Loss Support Group – visit: www.butterflies.org.uk
email butterfliesmlsg@yahoo.co.uk

Hull Breathe Easy support group –email joanne.l.thompson@hey.nhs.uk or karen.watkins@hey.nhs.uk or, for general help, contact the British Lung Foundation at www.blf.org.uk and helpline on 03000 030 555

Freedom Stroke Club – visit: www.freedomstrokeclub.co.uk

Feedback

I would really welcome your feedback on this report, so please do get in touch.

Email: publichealthfeedback@hullcc.gov.uk or julia.weldon@hullcc.gov.uk

Write to: Julia Weldon, Director of Public Health, Hull City Council, The Guildhall, Hull, HU1 2AA

Telephone: 01482 300 300

Tweet: @HealthHull using #DPH2019

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Golden Years

Healthier Longer Lives in Hull



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