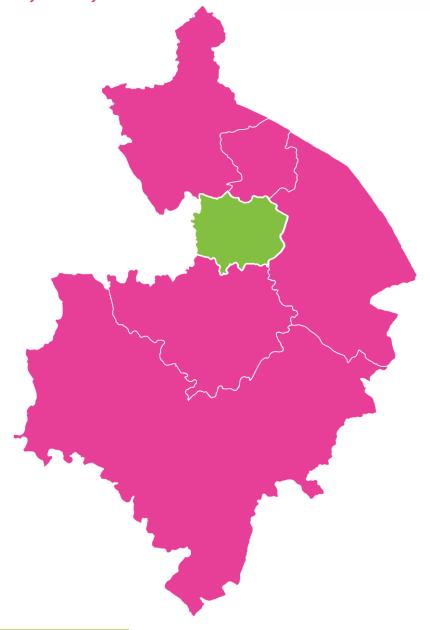




healthwetch

Coventry



NHS Long Term Plan

Coventry and

Warwickshire Report

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If you would like this report in alternative formats please contact Healthwatch Warwickshire at <a href="mailto:info@healthwatchwarwickshire.co.uk">info@healthwatchwarwickshire.co.uk</a>. We will produce these upon demand.

## **Executive Summary**

#### What is the NHS Long Term Plan?

The Government has announced that the NHS budget will be increased by £20 billion a year. In January, NHS England published an ambitious ten-year plan showing how this extra money will be spent.

The plan set out the areas that the NHS wants to make better, including:

- Improving how the NHS works so that people can get help more easily and closer to home. For example, being able to talk to your doctor on your computer or smartphone; access more services via your GP near where you live; use other community services which could improve your health; and leave hospital without delay when you are well enough.
- Helping more people stay well. This includes things like helping more people to stay a healthy
  weight or to stop smoking. It covers helping to tackle air pollution and making sure your health
  isn't worse because of where you live, the services and treatments available, and the amount of
  money you have.
- Making care better. The NHS wants to get even better at looking after people with cancer, mental health, dementia, lung and heart diseases, learning disabilities and autism.
- More money invested in technology so that everyone can access services using their phone or computer, and so that health professionals can make better, faster decisions.

#### What does this mean locally?

NHS organisations have been asked to come up with a local plan explaining how these priorities will be delivered in Coventry and Warwickshire. Healthwatch Coventry and Healthwatch Warwickshire are working together to find out what local people think. What people tell us will be shared with the local NHS and will be used to develop the local plan for Coventry and Warwickshire.

#### What did we do?

From March to April 2019, Healthwatch Coventry and Healthwatch Warwickshire launched two surveys: a general survey, which asked how to make care better and understanding what changes are needed to get people the support they need, and; a specific conditions survey, which asked about the health and care support that people received and what could be improved. The surveys were available and promoted online and were also used to engage with local people face to face (see the Surveys Methods section in the appendix for more information).

The table below sets out the number of responses by area:

	Coventry	Warwickshire	Total
General Survey	177	323	500
Specific Conditions Survey	105	190	295
Total	282	513	795

Simultaneously we ran focus groups to gain insight on people's thoughts on how to age well and the use of digital technology in supporting health and social care. These topics, Proactive and Preventative Care and the role of Technology in Health and Care, were the two priority areas we agreed for our focus groups after meeting with the Sustainability Transformation Partnership (STP). Healthwatch Coventry covered both these topics in their focus groups and Healthwatch Warwickshire used the focus groups to talk to people about the role of technology. Healthwatch Warwickshire also used the findings from an earlier wellbeing survey to look at Proactive and Preventative Care (see Deliberative Engagements methods appendix for more information).

The table below illustrates the focus groups and intelligence gathered on these specific themes:

Healthwatch Coventry	Healthwatch Warwickshire
Focus group - Asian Blind Association	Focus group - Age UK
<ul> <li>Focus group - Mental Health support</li> </ul>	Focus group - Newton Community Centre
<ul> <li>Focus group - Ageing healthily</li> </ul>	<ul> <li>Focus Group - Senior Citizens Luncheon</li> </ul>
	Club
	EQuiP - BME groups
	Online Engagement - targeted questions on
	the use of technology

#### What did we find?

The General Survey illustrated that respondents in both Coventry and Warwickshire would like to see improved access to healthcare and would like to feel like they have been listened to. People continued to tell us that they have problems with transport and would like to have more choice when it comes to when and where they receive treatment.

The Specific Conditions survey told us that when it came to support, seeing a specialist, and getting good timely communications. People with cancer had more positive experiences than people with other conditions. Those with specific conditions, such as autism, clearly indicated that they felt waiting times were too long and that they received little or no support. A large proportion of respondents told us that waiting times and accessing ongoing support continued to be a problem

The findings from both surveys were supported from the discussions in the engagement work we collectively undertook and Healthwatch Warwickshire's Wellbeing report.

#### What happens next?

The NHS in every area of England has been asked by NHS England to come up with a local plan explaining how they will deliver the priorities set out in the NHS Long Term Plan. The results of the survey should help the NHS in Coventry and Warwickshire invest in the right services. We will publish this report publicly and ask the local NHS how they will respond to these views in the plans that they produce.

#### Information about Coventry and Warwickshire

#### Hospitals in Coventry and Warwickshire



Coventry is a multi-cultural city bordering Warwickshire, with a population of around 400,000. In the 2011 census, 33% of the population identified themselves as from a Black and Ethnic Minority background. Coventry is the second-fastest growing Local Authority outside of London, with the biggest rate of growth amongst 25-29-year-olds. However, the number of older people is also growing, with 14% of the population over 65 years old.

The County of Warwickshire is a divided into five districts: North Warwickshire, Nuneaton and Bedworth, Rugby, Warwick and Stratford-on-Avon. The population is concentrated within the main towns, although a significant part of Warwickshire is rural in nature.

There are three NHS Clinical Commissioning Groups (CCG) that span over Coventry and Warwickshire; Coventry and Rugby CCG, Warwickshire North CCG and South Warwickshire CCG. They are clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for the local area. The main Hospitals in Coventry and Warwickshire are shown in the picture above.

The case study included below is an example of the promotion we did for this engagement work.



# Breast cancer survivor urges people to have their say about changes to the NHS in Warwickshire

More money should be invested in recruiting Clinical Staff in Warwickshire - that's the view of former cancer patient Susan Jenkins.

72-year-old Susan, from Leamington Spa, is sharing her views and encouraging others to speak out as part of 'What Would You do?', led by independent health and social care champion Healthwatch Warwickshire.

Retired bio-chemist Susan, who is also on several local breast cancer support groups, said: "We have a huge shortage of Clinical Oncologists in the area and the West Midlands has one of the lowest levels of Oncologists per head of the population in England.

"I would like to see the NHS spend more money on recruiting staff. The NHS does a wonderful job but there's just not enough of them out there".

Susan has had plenty of first-hand experience with health services in Warwickshire after being diagnosed 12 years ago with breast cancer. She had a lumpectomy followed by radiotherapy and has since been cancer free.

Her experience led her to volunteer with several support groups and Healthwatch Warwickshire to ensure patients have a voice in their care.

Susan continued: "By talking and listening to people who have been ill - you get fantastic knowledge and feedback about health services, which we will all have to use at some stage in our lives.

Patients are the experts, each and every one of them has a story to share - whether that's good or bad. I would encourage others to take part in this survey on how the NHS Long Term Plan should be implemented in Warwickshire and make sure their voice is heard".

People can share their views by speaking directly to Healthwatch Warwickshire.

Chris Bain, Chief Executive at Healthwatch Warwickshire, added: "The NHS only works when the voices of the people who use it are heard. This is a once in a generation chance for local people to help decide where this extra money from Government should be spent in our NHS services in Warwickshire. "We want to hear from as many people as possible about what works, what doesn't and how they think local health services should be improved. No matter how big or small the issue, we want to hear about it. Sharing your experience with us is quick and easy - and could make a big difference".

# Findings from the general survey

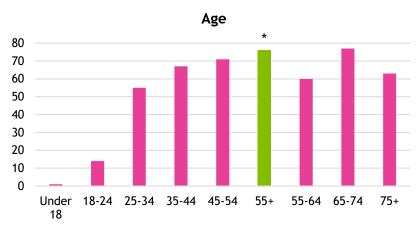
## **Demographics**

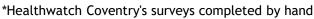
#### Area

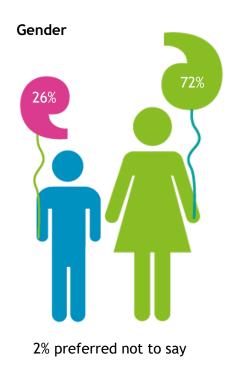
Coventry	Warwickshire	Total
177	323	500

## Who are you responding on behalf of?

Myself	Someone else	Total
352	140	492







## 23% considered themselves to have a disability

## 44% stated they have a long-term condition, 14% having multiple conditions

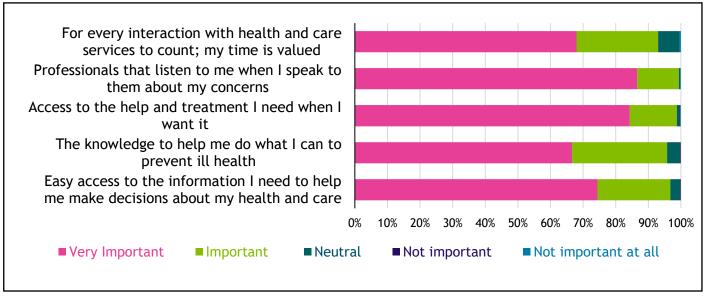
#### 15% reporting being a carer

Ethnicity	Count
White British	390
Any other white background	16
Indian	16
Asian British	15
Other	12
Any other mixed background	9
African	7
Black British	5
Pakistani	2
Caribbean	2
Gypsy or Irish Traveller	1
Total	475

Sexuality	Count
Heterosexual	412
I'd prefer not to say	38
Other	7
Bisexual	6
Gay or lesbian	6
Pansexual	2
Asexual	2
Total	473

The general survey set out a series of statements relating to four topics and asked respondents to state how important these were to them and to then pick which one was most important.

## What is important when it comes to having what I need to live a healthy life



Our findings demonstrate that respondents said 'professionals that listen to me when I speak' was very important, as shown in the graph above. However, when asked choose the most important, 48% selected 'access to the help and treatment I need when I want it'.

We asked, if there was one more thing that would help what would it be?



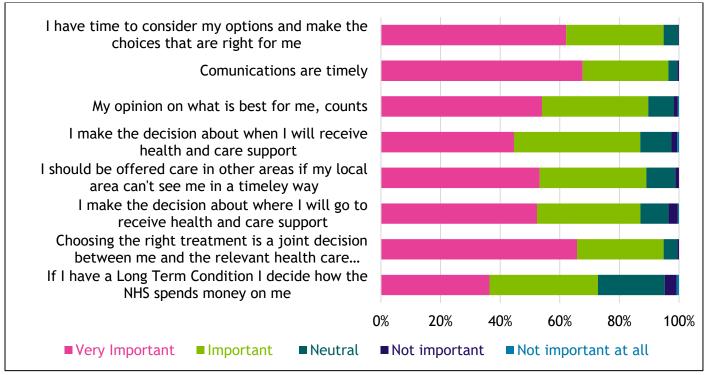
In support of the findings above, respondents said access to healthcare, when needed. They also commented that they wanted integrated services, to be

listened to, treated holistically- not just given prescriptions, and to be able to access good information and signposting when needed. They also said that they would like:

- Reduced waiting times "Access to medical advice when I need it, without the trauma of trying to get an appointment"
- More choice on ways to get help including health checks and access to specialists "A number of different ways to contact health professionals"
- Access to affordable healthy foods and physical activities "Access to community services and support. This might include things like access to affordable exercise classes and wellbeing classes and local produce"
- Access to transport, especially for healthcare
- Better environment, less pollution and traffic



### What is important when it comes to being able to manage and choose the support I need



\*LTC - Long Term Condition

When asked to pick the most important, 48% of the respondents selected 'Choosing the right treatment is a joint decision between me and the relevant health care professional'. 'Communications are timely' was also selected by the most people as being 'very important', as shown in the graph above. Only 4% said 'I make the decision about when I will receive health and care support' was the most important. This response differed for the Under 25's who most frequently selected 'I should be offered care in other areas if my local area can't see me in a timely way' (36%).

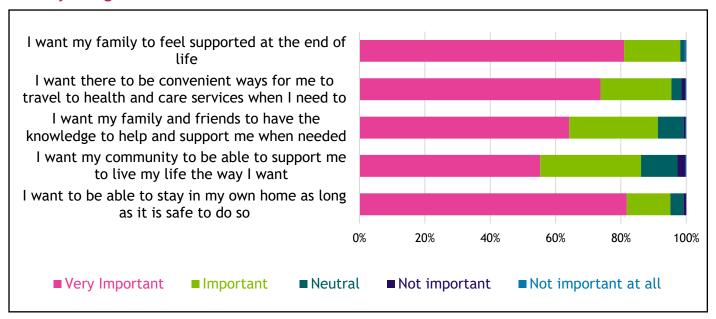
We asked, if there was one more thing which would help you what would it be?



Again, Access to healthcare was mentioned frequently; being able to get appointments (more quickly and flexibly), being listened to and the ability access results "To be able to get appointments quicker, both at the doctor's surgery, and hospitals. I had an appointment scheduled for 27th March 2019, for a yearly check at the hospital. This has been cancelled and put to 21st Aug 2019. That's 5 months later, which is appalling".

Respondents also spoke about having good quality, up-to-date information and signposting to services "Increased awareness of the services available in my area" as well as improved communication (both between services and services and patients) "Good communication and cooperation between my GP, the local hospital and my specialist centre in Birmingham."

What is important when it comes to the help I need to keep my independence and stay healthy as I get older



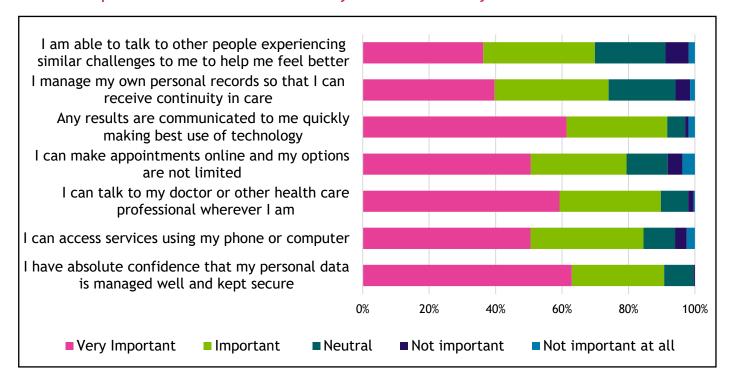
Over 80% of respondents said 'I want to be able to stay in my own home for as long as it is safe to do so' was very important to them. This was supported by 52% of respondents saying it was the most important factor in keeping their independence staying healthy as they get older. This was also the largest response when looking at age and ethnicity, however for younger people staying in their own home seemed to matter less and amongst Indian and British Asian respondents receiving support from the community of family and friends mattered more. However, overall only 7% of respondents stated "I want my community to be able to support me to live my life the way I want" when asked what was most important.

We asked, if there was one more thing that would help you what would it be?

In support of the findings the main responses concerned help to stay at home, these included:

- Have your say
- Home adaptations and equipment "Downstairs toilet and walk in shower"
- Better care services at home, community services and support "For services to be in place to support me, without having to rely on the community or family. This seems to be the way the government are proposing to move, ... in reality it means that many elderly people will be struggling to manage without support"
- More emphasis on staying well in their own home but also affordable care homes "Information on 'Care at Home' services, meals, care visits etc. Home or care home are not the only choices"
- Improved Transport links "Public transport is essential. Especially links with hospital and train services; at the moment it is poor"
- Better Diet and exercise

### What is important when it comes to how you interact with your local NHS



Respondents, when initially asked, rated that having confidence in how their personal data is managed and kept secure and how their results are communicated to them quickly making best use of data as the most important. When we asked which was most important however, only 17% of respondents selected this and most respondents (37%) said, 'I can talk to my doctor or other health care professional wherever I am' which had ranked third in the initial question. Only 3% said 'I am able to talk to other people experiencing similar challenges to me to help me feel better'. Overall younger respondents found the statements were more equally important.

#### We asked, if there was one more thing that would help you what would it be?



A key theme which arose when answering this question was having an alternative to online, many, particularly the elderly or those who cannot afford technology/access to the internet are concerned about being put at a disadvantage. There were also repeated concerns about security. "Technology should not always be relied upon due to vulnerable groups such as the elderly and people with learning disabilities who will find this method of communication very difficult.

Putting the person first is a priority and if that means using methods of communication and tools to communicate that doesn't rely on technology this should happen. Too many vulnerable groups are missing out on vital information because of technology"

"That if I do not access to online I am not disadvantaged in any way. You should not design in inequity to services based upon IT access"

Many however, did want to be able to access services information and book appointments online "Making appointments online with availability for quick and easy access to a health professional when I need one". Other main comments, many of which reiterate the earlier themes, included:

- Access to GPs, ease making appointments, when needed, both by telephone and in person and to see a GP as soon as possible. Respondents also wanted flexible services operating outside of 9-5 "Access to see a doctor when needed, not 2 weeks down the line, as is the case if your trying to get an appointment"
- Access to medical records "To have access to my own records and be able to discuss any queries with someone who understands"
- Communication, patient records and communication to the patient "Make the systems used across health and social care speak to one another effortlessly ensure that services are truly seamless"
  - "The medical records need to be all joined up. Referrals are sent with no notes so you have to relay the information"
- Access to results, information and regular check-ups

## Findings from the long-term conditions survey

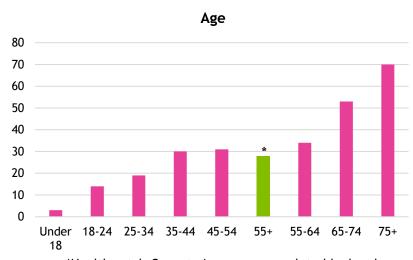
## **Demographics**

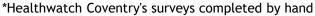
#### Area

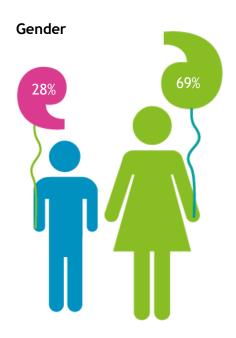
Coventry	Warwickshire	Total
105	190	295

#### Who are you responding on behalf of?

Myself	Someone else	Total
188	106	294







3% preferred not to say

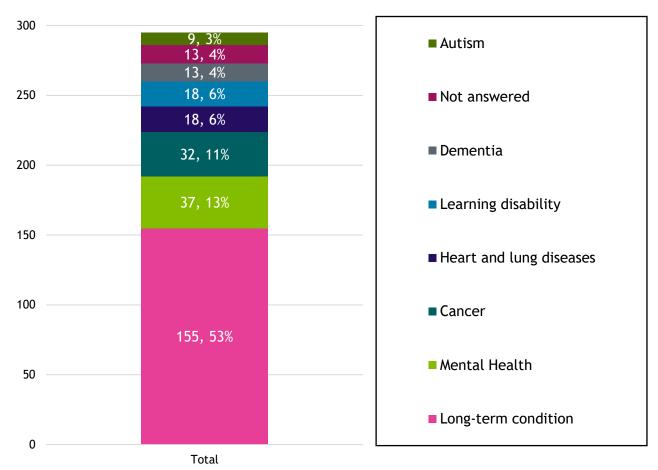
## 54% considered themselves to have a disability

### 24% reported that they were carers

Ethnicity	Count
White British	218
Asian British	26
Other	13
Indian	9
Any other white background	4
Caribbean	3
Pakistani	2
Any other mixed background	1
Total	276

Sexuality	Count
Heterosexual	206
I'd prefer not to say	20
Bisexual	9
Other	8
Gay or lesbian	3
Pansexual	3
Asexual	2
Total	251

## What condition would you like to tell us about?



Most respondents wanted to tell us about a long-term condition which did not fall in to the six other categories (53%). Examples of these included, but are not limited to, conditions such as: fibromyalgia, diabetes, and arthritis. The next highest responses were for mental health (13%) and cancer (11%). There is a relationship between age and condition in that respondents telling us about a long-term condition, dementia or cancer, tended to be older and those telling us about mental health or autism tended to be younger.

#### 32% told us that the condition they were telling us about started in the last 3 years

Again, there was a relationship between when their condition started and the condition. A higher proportion of people with autism, learning disabilities and long-term conditions said their condition hadn't started in the last 3 years.

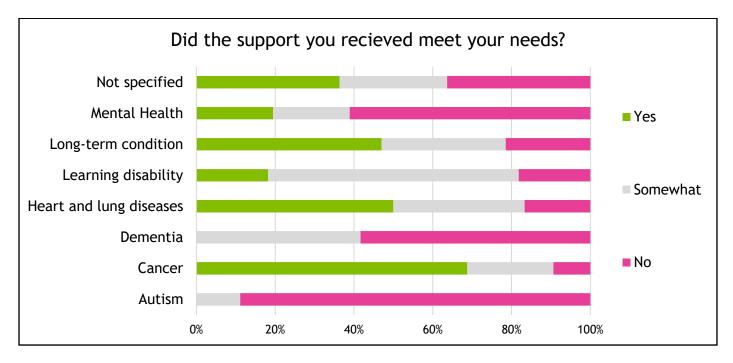
For the long-term conditions survey we asked people to talk to us about their experiences of using health and social care services throughout their journey, as well as their preferences. To help show the results we have developed a key:

Green shows better experiences and pink more negative experiences



## When first accessing help

Overall, 41% said the support they received met their needs but 29% felt their needs were unmet.



As shown in the graph above, cancer, heart and lung disease patients reported the support they received as meeting their needs (69% and 47%, respectively). For mental health, dementia and autism the finding was much less, the majority instead reporting that their support needs were not met and no respondents for dementia and autism reported their support needs being met. These findings were supported in a later question where we asked respondents to describe their overall experience of getting support on a scale from very positive to very negative and a similar picture emerged.

When asked how the support had met their needs respondents told us that quick diagnosis and referrals had made a difference.

"Due to the family history of chronic heart disease I was seen urgently and by several specialist services"

Good support, no problems as all of my questions were answered"

#### "My GP diagnosed me and within a month I had an appointment with a neurologist"

When asked how it could be improved respondents again said that **fast referrals and fast and correct** diagnosis mattered.

"There was an 18-month delay in getting the support to the individual"

"It was a slow process to get a diagnosis and the appointment times/days were limited"

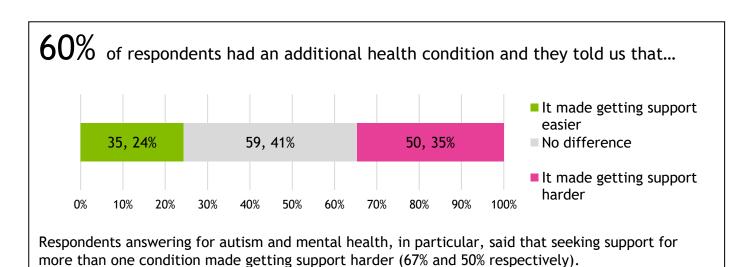
"By having GPs who listen to patients and get diagnosis right"

We were also told that respondents wanted more support for those in crisis, to be taken seriously and not just given medication, as well as having more support for carers and better information and signposting given generally and when leaving hospital.

"Severe issues referred to IAPT service which is for mild/moderate only, and they were not able to deal with me being suicidal and self-harming"

"My first GP was a locum and didn't take my concerns seriously.

Fortunately, I went back and got a referral as it turned out to be breast cancer"



## How would you describe the time you had to wait

Overall, for their initial assessment, nearly 50% of respondents told us that they felt they had waited for a long time, rating their experience as either very slow or slow (compared to less than 25% describing the time they waited as fast or very fast).

Similarly, both when **receiving treatment** or **seeing a specialist** nearly 40% described their experience as slow or very slow (compared to just over 25% as fast or very fast).



We found that 90% who were waiting to see a cancer specialist described their experience as either 'very fast, fast or ok'. Conversely respondents told us that when waiting to see a mental health specialist or autism specialist the waiting times were very slow (50% and 100%, respectively).

When we asked patients to tell us more about waiting times; we received a mixed picture where some Cancer patients reported seeing a specialist on the same day but in one instance, we were told that a patient had to wait three months to see a specialist. For respondents telling us about their experiences with **mental health** specialists we had one instance of only having to wait three weeks this increased to over a year and with **many citing waiting around six months**.

"5 months wait is too long when you feel like every day you're failing and falling apart, and letting everyone down and struggling with suicidal thoughts"

When looking at waiting times for initial assessments and receiving treatment there is a similar picture. Respondents who told us about their experiences relating to Autism stated waiting times as 'years' due to trouble in getting a diagnosis. Those with Mental Health described their wait as 'months and years' with many stating that they had been passed between doctors, hospitals and other services and some stated that they did not receive any help as the support they need wasn't available. Waiting times for mental health services, including Child and Adolescent Mental Health Services, featured throughout the survey.

"I waited 3 months for CBT but that was not what I needed. I then waited 4 months for counselling.

Then waited 8 months to be seen by the mental health team. I am looking at 6 months for psychotherapy"

Respondents who stated they had Cancer reported that they did not have to wait very long, several being seen the same week. However, one respondent told us they had waited two years.

"From my initial smear test to diagnosis it took nearly two months which I thought was quite a long time to be hanging around in limbo not knowing. Speedier diagnosis would have helped"

### Health and Care support after initially seeking help

76% of respondents told us they were referred to a specialist. 53% told us they were offered access to further health and care support. We asked them what could be improved and what aspects worked well.

Respondents told us what they thought had worked well, this included, but was not limited to; Medication, members of Staff, Support Groups, Therapies/Treatments, Desmond for Diabetes, Physio and Nurses. When asked what aspects could be improved, respondents told us that; support sessions were not long enough, they wanted to be listened to and would like more on-going support.

"Had IAPT face to face appointments but they were not long enough.

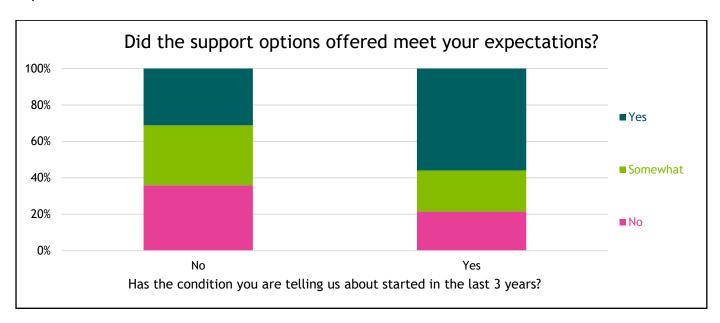
I felt I was dumped after 6 sessions just when I began to trust my counsellor"

"It was excellent I couldn't fault it. The problem was with the ongoing check-ups.

The people who did them initially seemed to have little or no interest in us"

37% of respondents found it difficult to access ongoing support compared to 24% who found it easy. When we looked at specific conditions nearly 60% of people experiencing cancer told us it was either 'very easy or easy' to access ongoing support. Over 60% of people experiencing mental health issues told us that they found it either 'very difficult or difficult', as did 70% of people with dementia and 100% of people with autism.

Overall 39% of respondents stated the support options offered met their expectations, 31% said they did not. When looking at dementia only 12% felt that their support options were being met whilst people with Autism said that their needs were not being met (0%). Conversely, for Cancer, 78% said their expectations had been met.



When we asked respondents if their condition had started within the last three years, we noticed a difference in the perception of the support options being met, as shown in the graph above. When the respondent's condition had started in the last three years almost 60% of respondents found that their support options had been met. Whilst if the respondent's condition had not started in the last three years this reduced to around 30%. However, this difference could be partially explained by differences in conditions such as a Learning Disability or Autism which may have only been recently diagnosed.

We asked for experiences of how expectations had been met and what had been difficult. Many respondents said that they had a positive experience with receiving support with particular praise for specific teams within organisations. Respondents said that they had difficulties with navigating the 'system' and booking appointments, and many told us that they feel 'lost' and 'alone' still waiting for support, this is illustrated in the case below.

"Aylesford centre staff were excellent at dealing with problems, giving answers and organising support such as a dietician etc. at Warwick Hospital.



The care was excellent once I received it. It was exactly what I expected and was effective. In my case, this was CBT for OCD. I was also able to access medication immediately. This was initially prescribed privately by my psychiatrist and then as

a repeat prescription from my (NHS) GP. This was very useful.

I was not contacted by the support team and when I saw them in the clinic, I did not feel that I had the opportunity to talk with them as they were rushing about.

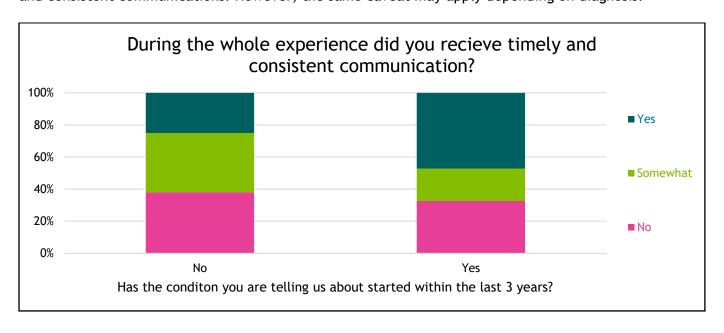
My husband was left on his own to look after me as I had chemo, 2 operations and was very ill as I had so much weight loss as well. It was down to my husband on his own to look after me

Ongoing support is not really available. You are expected to get better and move on, but many people are mentally ill for years if not their whole lives. I have exhausted all the options the NHS has for me.

We weren't offered any support by the Hospital or Nurse. Any support we have we have found ourselves. There is no joined up thinking between the NHS (Specialists and Consultants and GPs), Social Care (WCC) and the voluntary sector".

#### Communication

Overall there was not much difference between whether people thought they received timely and consistent communication (33% said they did, 36% said they didn't). When we looked at specific conditions however only 18% with dementia and 11% with mental health said that their communications were timely and consistent. Cancer again fared much better with 64% reporting that they received timely and consistent communication. As reported previously, those whose condition had been diagnosed in the last three years reported a better experience in receiving timely and consistent communications. However, the same caveat may apply depending on diagnosis.



We asked about **people's experiences of communication.** Respondents told us about timely care and good experiences with staff. They also told us that there was often poor communication between hospital departments, GP's and patients. Respondents said that patients and carers often felt as if they were alone and unsupported in diagnosis and the receiving of care and treatment, as shown in some of the quotes below.

"After the consultation, I needed to have exploratory treatment which was done within a month or two if I remember correctly. Then I had surgery very soon after".



"The communications with the hospital were fantastic. They were clear, comprehensive and timely. On the other hand, communicating with the GP surgery is a nightmare! They need to ditch the fax machine in favour of email/Skype/etc!"

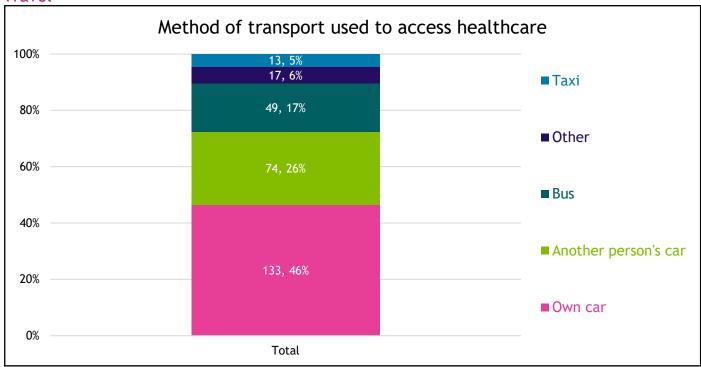
"I have found communication to often be poor. Left hand does not know what right hand is doing. GP practice and hospital letter unclear"

"Care for my mum was pretty much down to our family to resource identify and fund, the only support that I got was from the carers trust that provided advice and sign posting for matters relating to attendance allowance and other basic elements of support"

"Having a diagnosis made little difference health wise any help was obtained via the education system. It was almost as if it was a case of you have a diagnosis now get on with it"

"I expected support: however, staff are overwhelmed, waiting times are long, and group sessions are not appropriate"

#### **Travel**

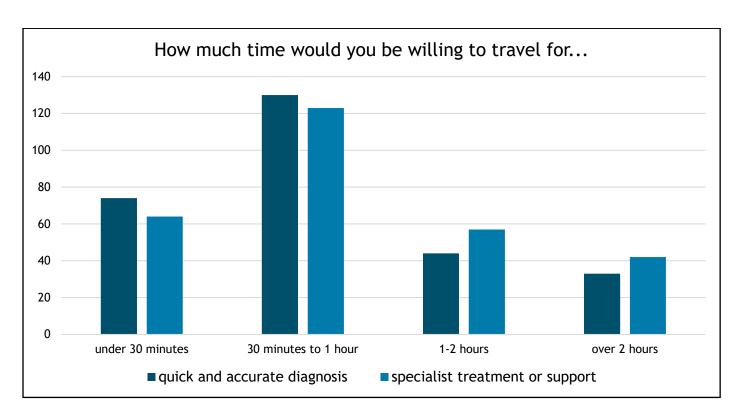


When we asked people what method of transport they used to access healthcare, 72% of respondents told us that they either used their own car or got a lift from someone they knew.



"I have nobody who can take me to hospital. I usually drive myself. When I have an exacerbation, I am too ill to drive and there is no transport for me. These arrangements should be part of a package of care and treatment associated with the specialised department and ward of the hospital which I attend. The feeling of being 'dropped in a hole' causes a lot of anxiety"

Transport has been a recurring theme throughout this piece of work, featuring in two out of four topics in the general survey. Healthwatch Warwickshire reported that it was one of the most prevalent themes arising from our recent Wellbeing survey. While only 17% reported using public transport we know it is a prominent issue for them, particularly in rural areas. As is car parking for those who travel by car, particularly at UHCW. Without further investigation it would be hard to determine whether the reason people are taking their own cars is because of their perception of unsuitable public transport alternatives or not.



As shown in the graph above, the largest number of respondents reported being willing to travel 30 minutes to 1 hour to access care but were generally willing to travel slightly further for specialist treatment than for a diagnosis.

Upon further investigation, those living with Mental Health or Dementia are less willing to travel longer times for healthcare (80% stated they would be willing to travel less than an hour). For specialist treatment or support those with Heart and Lung disease or a Learning Disability were willing to travel for longer (over 25% being willing to travel more than 2 hours).

### Your expectations at each stage of your care

What is more important to you?

	Seeing a health	Seeing any medically	Don't
	professional you	appropriate health	mind
	normally see but you	professional who is free	
	may have to wait	immediately	
When first seeking help	38%	37%	25%
When you first received a diagnosis and	46%	35%	18%
explanation of the treatment options			
During your initial treatment or support	45%	36%	19%
During your long-term support	56%	24%	20%

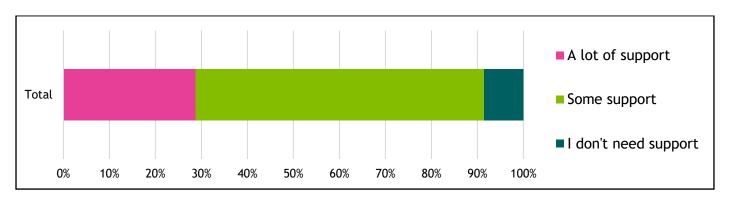
The table above shows respondents preferences towards either: waiting for a known health professional or seeing any appropriate health professional but sooner, and how this preference changes for the different stages of care. Preference for seeing one's normal health professional increases the further along the care journey, though this was always the most common response.

However, when looking at different age groups, the majority of those under 45 selected any professional who is free immediately for the first two stages of care: first seeking help and receiving a diagnosis. When it came to treatment and support, both short and long term, this effect was mitigated.

There is also a difference of preference depending on the condition. For first seeking help it was only the general long-term condition group selected seeing their normal health professional over any professional sooner, for conditions such as dementia and cancer it was the other way around. For the next two stages, diagnosis and treatment, more respondents telling us about cancer and mental health opted to see someone quickly. But for long term support it was again the case that respondents wanted to see someone they know regardless of their age or condition.

#### What level of support would you like the NHS to provide?

91% of respondents would like some level of support with 29% telling us they would like a lot of support



There is little difference between conditions for the level of support expected, however learning disabilities had the highest numbers reporting they needed a lot of support and dementia the least. Conversely, for those who reported needing no support the largest number was cancer patients, and the lowest was people with autism.

Finally, we asked: What could the NHS do to help you stay healthy or manage your condition? The main themes of the responses and some illustrative quotes are shown below:

#### Providing regular checks and check ups

"Run a well woman clinic to see elderly people every 6 months, also monitor prescription medicines every 6 months. I have had a repeat prescription for years only checked once."

#### Better communication and information

"... Patients informed of treatment process, their personal care plan and expectations from both sides (service/patient) from the beginning with periodical updates."

#### Having a named or known health professional

"It is really important for me to see a doctor that knows about my history as I often need to ask for antibiotics that work for me (when treating chest infections). These drugs are not the ones you would usually start with."

#### Access to knowledgeable and trained staff

"It would help to know that there is someone available who has a reasonable understanding/amount of knowledge and experience of autism. It is a challenging condition to live with and it is a challenge to provide support for the individual with autism. Considering the number of individuals that now have a diagnosis there still appears to be a lack of information/training available."

Receiving timely service (in all aspects of care) and more time with health care professionals

"Provide access to professionals when I need them and information about my condition when they find out that there are alternative treatments or improved treatments."

#### Pain management

More Mental Health support in the community

"Provide more after care. I have never been offered any counselling or help for coping after treatment. just cast back out into the world and expected to carry on with life as normal."

#### Joined up care

"Work with the other areas of the Health Service involved with Dementia, work with LAs, voluntary organisations. Dementia is different for everyone. All the providers need to work together to provide a seamless service."

We also received much positive feedback from individuals thankful for the NHS. Many praising, frequency of check-ups and the quality of services they already receive.

"In my case, ongoing therapy until I have the ability to support myself would help me manage my condition, but this is already what my local NHS service provides."

## **Engagement activities**

As part of the NHS Long Term Plan (NHS LTP) engagement Healthwatch Coventry and Warwickshire were asked to undertake focused engagement in order to gather the public's thoughts on the NHS LTP and their views on particular elements of the plan such as; Cancer Care, Mental Health, Digitisation etc. and what that would mean for the local implementation of the NHS LTP in Coventry and Warwickshire. Coventry and Warwickshire both looked at the use of technology in healthcare and how to age well.

Together we held six focus groups in Coventry and Warwickshire and collected other intelligence through EQuiP (Warwickshire Equality and Inclusion Partnership) and using online engagement.

#### Healthwatch Coventry - focus groups

Healthwatch Coventry engaged with 38 people over three focus groups. Each of the focus groups looked at information relevant to their groups such as, mental health and how to age well, as well as discussing the use of technology in healthcare.

From the equalities information collected; 21 of respondents were female; 15 were male and 5 did not respond. Only two of the groups provided information on ethnicity and this could be grouped into White (8) and Asian/Asian British (14). 14 of the respondents were aged 65+ and 7 were between 35-65 years of age.

In two of the focus groups the discussion focussed on **how to age well**. Key themes that came out of these groups included:

That they knew how to age healthily but the barriers included; motivation, support and cost.

Community services/voluntary sector- the Asian Blind Association were unable to provide a list of community support services that could help them age well, whilst the participants of the 'ageing healthily group' provided an extensive list of services, this illustrated the knowledge gap in what services are available. Both groups agreed that these services could be useful/essential in the ability to age well.

"It would be better if the GP/nurse practitioner could recommend a greater variety of physical activity and community groups"

-Member of the Ageing Healthily group

**Social isolation** - the Asian Blind Association participants noted that there could be an issue around social isolation if people remain at home for long periods of time and that this could result in health-related issues like depression.

**Transport** - both groups picked up on transport being an issue in Coventry. The Asian Blind Association had concerns about a local service 'Ring and Ride' that had gone into administration and that they had little alternatives to use. They did not want to have to depend on family and friends. The 'ageing healthily' group stressed that there was a need for non-emergency transport and that it would be useful to be able to use their bus pass more widely which would enable them to see friends and family as well as travelling to health appointments, overall reducing social isolation.

"Being able to travel independently to see family and friends. It would be better if older people could access discounted bus travel etc. (to help with medical appointments and mental/social health)"

- Member of the Ageing Healthily Group

One of the focus groups who were identified as having mental health support needs looked closely at mental health services. Key themes included in their discussion:

**Prevention**- participants thought that there should be emphasis on ensuring that young people do not have to enter services in the first instance. The group thought that young people's services should include support on self-esteem, the impact of relationships, and social media.

"More work into preventative care. Holistic approach to long term conditions focusing on the cause of Illnesses"

Member of the Mental Health support group

**Support/Provider services** - participants felt that access to services should not only be available to those in crisis. That there should be more community support like family hubs. The group noted the benefit of services like street triage teams were good but there was a need for mental health charities to have extended opening hours. The group said that there was no directory of services available due to funding cuts as this information was now only available online it restricted access.

**Funding** - There was a strong consensus that there had been a lot of 'deletion/merging' of services and that this resulted in less choice for the user and therefore a reluctance to go to support groups. The group identified that there was a need for more investment in family hubs and crisis support. Quotes from the group included;

"There used to be lots of support groups now there are fewer"

"They (a mental health charity) bid for funding then squeeze people into a one-size-fits-all,
then people don't go"

Members of Mental Health Support Group

**Referrals** - the group thought that there was a need to change the GP referral system particularly in relation to prescribing:

"For instance, a GP cannot refer someone to a CPN or psychiatrist until a crisis has occurred.

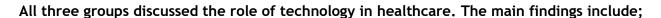
There needs to be more services for prevention"

Members of Mental Health Support Group

#### Recommendations from all three groups in Coventry:

- Continuity of care (only having to tell your story once, feeling in control),
- Access to services,
- Good information and signposting service,
- Good community support,
- Staffing shortages to be addressed,
- Ring-fenced funding for Health and Social Care for 10 years;
- Quality support services, and
- Investment in services

'feeling done to rather than being involved in the decision making about their care'



Access - all three groups had concern about the access to services and access to using technology and internet. One participant in a focus group claimed that "one fifth of Coventry homes are without an internet connection". Participants were in favour if it helped them access healthcare:

"If there is something that helps, this is good for me. There is no point in phoning for an appointment, by the time I get through all the appointments are gone. I wait outside the surgery whatever the weather at 8.00am, there is no shelter, when I am feeling ill, just to get appointment, how is that right for people who are ill"?

"For those who are able to use technology to access GP services it would be good to be able to check drugs (to find out contra indications etc)"

"It is difficult to access information about these groups if you're not online"



"Online you can see when a doctor is free, and this was much better than calling at 8am, it's a more efficient service for prescription ordering online, don't have to deal with fuss, save GP money, good for people who have issues with mobility"

Quotes gathered from all three focus groups

Cost - All three groups voiced concern over the cost of technology and internet subscriptions with the Mental Health group noting that the general feeling of the group was that as many of them did not have smart phones or immediate access to the internet, they felt that this would put them at a disadvantage when accessing services. All three groups had concerns about this resulting in a two-tier health and care system.

An excerpt from the write up from the Asian Blind Association focus group: There was some concern that the introduction of technology would put them at a greater disadvantage as they would be unable to use technology. As this group broadly didn't use technology, they felt that in order to get equity of access to services they would need a lot of help in education, would incur a lot of expense and an additional monthly bill (internet and mobile phone charges) just to access healthcare.

**Integrated care and single patient record** - one group identified ensuring that health and social care worked as one was important. There was a need for the integration of services and that having a single patient record would allow patients to only tell their story once.

"If the services cannot be properly integrated then they will blame each other for underperforming"

-Member of the Ageing healthily group

## Healthwatch Warwickshire - focus groups, information received and online engagement

Healthwatch Warwickshire focused their engagement around the use of technology in healthcare. They ran three focus groups reaching 35 people, primarily older people and spoke with EQuiP (Equality and Inclusion Partnership) about the experiences of the BME community whilst running an online engagement survey to ask the people of Warwickshire specifically about their experiences with technology and healthcare.

There were positive and negative experiences when we discussed technology, some acknowledging it is "the future", whilst others not using it at all. The main themes discussed at all groups included:

- Access all groups identified that not all people will have access to technology or the internet.
  Some attendees thought that digital services were easy to access, whilst others found it frustrating or did not have an interest in doing so, several relied on relatives or using the phone.
- **Information and signposting** one group clearly identified that they used online services and that they used technology to gather information and to get telephone numbers.

- Disadvantage/two-tier system one group identified that they thought if you did not have the
  ability to access information services online then, as a result, you could receive a second-rate
  service, indeed this was the current experience for some (e.g. when booking blood tests)
- Patient records and Information sharing all groups said that they would like to have access to their records and their records to be shared to ensure that they only have to tell their story once, and their records can be updated (single patient record) so there is better communication and information sharing between health care systems/services.
- **Data protection** one group said that they had concerns about data protection and website/records being hacked.

#### **EQuiP - BME groups**

"From conversations that I had with BME elders; they are very digitally excluded. The established BME groups, namely South Asian and Caribbean struggle with going online... this was also mentioned in our Equality Survey. The example given was booking in for a blood test at St Cross Hospital in Rugby. If you book online, you are seen more or less straight away, however if you do not book in online you have to wait a considerable time.

From our Dementia project, it was evident that BAME elders, and indeed elders in general, do not access the internet for information. The Dementia Portal with all the information on is accessible online however, for those that are digitally excluded (this includes their carers) finding this information is difficult. They have to rely on children and/or grandchildren for this information which is not ideal."

#### Healthwatch Warwickshire - online engagement

As part of our investigations around technology and healthcare we asked two questions:

- 1. What one thing would you change to improve your experience when it comes to technology and healthcare? Responses included; having the ability to email health professionals with concerns (including doctors and nurses), having the ability to access your records online, booking appointments online, having a single patient record where records are updated instantaneously, access to results, one stating that still having the ability to see professionals face to face, standardised patient database and one person saying that it was of no use at all especially to the older generation.
- 2. What do you think of the use of digital technology in Healthcare? A respondent said that they did not like others being able to see personal information, that they liked the online booking procedure and that it was better than speaking to receptionists whilst another found it frustrating as it did not work reliably.

#### Healthwatch Warwickshire - Wellbeing survey

Coventry and Warwickshire Year of Wellbeing 2019 was announced last year by the Coventry and Warwickshire Place Forum. As champions of the patient voice, Healthwatch Warwickshire wanted to better understand what wellbeing means to people, and what people thought would improve their wellbeing. We ran a survey at the end of 2018 for three months consisting of one question:

"What do you think would improve your wellbeing?"

We received 400 responses and the main findings illustrated that people would like:

- Access to GP appointments (availability, extended hours, easier booking services)
- Improved Healthcare (transport and parking, availability of medication, coordination and communication of services, treatment by staff)
- More Mental Health support (quicker responding services including in crisis)
- Improved Transport (particularly buses)
- Increased Connection (with friends and family, community)
- More support for Carers (particularly respite)

You can find a link to the full report in the references section (page 33).

## **Conclusions**

## Summary of findings

When asked to pick the most important, 48% of respondents said they wanted "access to the help and treatment I need when I want it".

Key themes that arose from engagement activities and both surveys illustrated findings that are consistent with what we hear in our day to day work at Healthwatch as well as our recent wellbeing survey. Some of the key findings illustrate that people would like to see:

- **Shorter waiting times** for GP appointments, appointments to see a specialist and access to necessary support
- A more holistic approach to care, not just being given prescriptions but instead using care in the community, and support groups, as well as exercise, diet and a better environment for people (such as tackling pollution)
- Access to GP appointments people would like to be able to access appointments with their GP more easily and benefit from longer opening hours
- **Better transport** people continue to tell us that they are unhappy with the availability of transport, this includes, but is not exclusive to, public transport particularly in rural areas. This was also a finding in a recent Healthwatch Coventry report (see reference on page 33)
- Communication respondents would like to see improvements to how their records are managed and accessed as well as receiving timely, clear and consistent information from health professionals. A lot of respondents told us that they would like to see better communication between services.

When asking about experiences of healthcare, these were comparatively poor for autism, mental health, and dementia. For example, when asked about waiting times, access to on-going support and communication people with these conditions reported worse experiences overall. On the other hand individuals responding with cancer or lung and heart conditions reported more positive experiences, however this is not to say there were still not negative experiences.

When asking about respondents' preferences, regardless of age or condition, we found that for on-going support patients would rather wait to see a healthcare professional they already knew than see any appropriate healthcare professional sooner. We also found that individuals mostly selected being willing to travel between 30 minutes to 1 hour for healthcare and would travel for longer to see a specialist.

The role of technology in health and care was a big theme in this work but also continues to come up as part of our ongoing engagement work and was therefore one of the agreed areas of work to look at with our focus groups. While many were in support of the role technology in health and care, wanting to be able to book appointments and find out information more easily online, there were many concerns and experiences where individuals felt they were at a disadvantage if they could not use technology, for

example, to book appointments. In Warwickshire this was mostly for older residents or family members expressing concerns on behalf of an older relative. However, in Coventry other issues arose around access to technology, particularly around affordability.

"There is too much reliance on technology which many people in my age group are not able to use. We require easier access to GPs, better transport to hospital and/or more and cheaper car parking. Local access e.g. to blood tests."

Another priority area was to look at proactive and preventative care particularly around wellbeing and ageing well. Many survey respondents wanted better access to services in their community including primary care services, this is a particularly big issue when it comes to getting an appointment when you need it, which is evident throughout this report. There is also an emphasis on better and more affordable diet and exercise, as well as transport being available to individuals, which are often cited as barriers to improving their wellbeing. In addition to these themes, in the focus group run by Healthwatch Coventry, which focused on ageing well, participants emphasised prevention, social isolation and funding as key issues. This again corroborates many of the findings from Healthwatch Warwickshire's Wellbeing report.

#### Limitations

- This survey looked at Warwickshire and Coventry as a whole. In our further engagement work we
  would like to look in more detail at the different 'Places' which Coventry and Warwickshire
  Health and Care Partnership have developed, namely: Coventry, Rugby, Warwickshire North and
  South Warwickshire.
- While we received a large amount of survey responses, enabling us to look at the information we have gathered in more detail, some of the numbers of responses for particular groups were quite small, for instance, the sample size for Autism for instance was only 9.
- The participants for the Warwickshire Focus Groups were primarily older residents.
- There were also several limitations of the survey itself. We often found the wording and repetitive nature of the survey frustrated and confused some respondents.

#### References

- Healthwatch Warwickshire's Wellbeing Survey www.healthwatchwarwickshire.co.uk/wp-content/uploads/2019/02/HWW-Wellbeing-Survey-.pdf
- Healthwatch Coventry's Getting to Outpatient Appointments Report www.healthwatchcoventry.co.uk/getting-out-patient-appointments

## Next steps

This was a great opportunity for Healthwatch Warwickshire and Healthwatch Coventry to work jointly on this piece of engagement, as well as with our colleagues in the NHS. We have learnt from this initial stage and look forward to applying this to the next phase of work, looking in more detail at some of key themes and findings of this work, both in Coventry and in Warwickshire. We will use this information to continue our work with the Coventry and Warwickshire Health and Care Partnership (formerly the STP), bringing these findings to other key partners such as to the Health and Wellbeing Board.

Response from the Head of Engagement and Communications for Coventry and Warwickshire Health and Care Partnership (Formerly the STP)

The Coventry and Warwickshire Health and Care Partnership thanks Healthwatch Coventry and Healthwatch Warwickshire for providing the engagement report for the NHS Long Term Plan. The insights and feedback gained through this engagement are a valuable resource to help inform and shape the future health and care system in a variety of ways.

In the first instance, the report will feed into a wider engagement review for the whole health and care system, the purpose of which is to identify common trends and themes, such as the importance of access and person-centred care, which have come from all of the engagement work across the system to date. It will also help to identify gaps in our evidence and understanding of the needs of our population and potential areas for further, targeted engagement.

This report is a single but important step in a much larger programme of engagement and we look forward to our continued partnership with our local Healthwatch organisations to improve the health, wellbeing and outcomes of our entire population.

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# Appendix: Methodology

#### Surveys

Healthwatch Coventry and Healthwatch Warwickshire launched two surveys: a general survey, which asked how to make care better and understanding what changes are needed to get people the support they need, and; a specific conditions survey, which asked about the health and care support that people received and what could be improved. The surveys were available both online and in paper, and available in different formats, Healthwatch Coventry using the easy read versions of the survey.

#### Timeframes:

#### March-April

- Engagement on the NHS Long Term Plan
- Promoting Surveys

#### May-June

- Holding Focus Groups
- Analysis of survey data

#### **Engagement Methods:**

Healthwatch Warwickshire and Coventry sent copies to and attended groups, events and meetings, engaging with individuals about the NHS Long Term plan and promoting the survey. We also sent out paper copies to various groups with a freepost address.

Some of the community groups Healthwatch Coventry talked to included: Coventry Older Voices (COV), Headway, Women of Willenhall, Bell Green Community Centre, Moat House Lunch Club, WATCH Hillfields, Parkinson's Society, Life Path Trust, Arthritis Action, Alzheimer's Society, Involve, Innini, Muslim Resource Centre, and Penderels Trust.

Healthwatch Warwickshire attended or sent the survey to groups/events including; Kenilworth Fire Station Open Day, Senior Citizens Luncheon Clubs, Mums and Toddlers Groups, South Warwickshire CCG Diabetes event, Westbury Community Café and Food bank, Age UK Warwickshire, Hope4, Doorway, Mary Ann Evans Hospice.

Healthwatch Warwickshire also ran two paid promotions on Facebook for both the surveys (see example)



#### Data Management:

Consent was obtained as part of the survey. Data was collected anonymously, with an equalities information for at the end. In Warwickshire paper copies were entered into the online survey and shredded and in Coventry the data was entered to an excel spreadsheet.

The data from the online survey was sent to us on a password protected excel spreadsheet from Healthwatch England and this was combined with the manually entered data from Healthwatch Coventry and stored on password protected computers.

Excel Pivot tables were used to help analyse the data and investigate the responses to questions using the other responses (such as Age or Long-term conditions) as variables- looking at the effect this had. Graphs were produced using Excel to illustrate these findings and differences.

#### **Deliberative Engagement**

We ran focus groups to gain insight on people's thoughts on how to age well and the use of digital technology in supporting health and social care. These topics, Proactive and Preventative Care and the role of Technology in Health and Care, were the two priority areas we agreed for our focus groups after meeting with the Sustainability Transformation Partnership (STP). Healthwatch Coventry covered both these topics in their focus groups and Healthwatch Warwickshire used the focus groups to talk to people about the role of technology.

#### Timeframes:

#### April-May

- Engagement on the NHS Long Term Plan
- Coventry Focus Groups and write ups
- Warwickshire Focus Groups and write up

#### **Engagement Methods:**

Healthwatch Coventry ran three focus groups with the following groups.

- Asian Blind Association
- Mental Health support
- Ageing healthily

All groups were given an overview of the NHS long term plan and asked if they had heard about it. Some of the questions asked to all groups included: What do you think the pros and cons of having technology in healthcare are to you? Which of these services (as listed by participants) should be kept? What new services are required in Coventry to help people stay well for as long as possible? What matters most? There was a little variation between groups to ask about particular topics, for example the aging healthily group had an introductory discussion on what ageing healthily meant to them and were asked what services they use that help people age healthily.

Healthwatch Warwickshire focused their engagement around the use of technology in healthcare and ran four engagement events. 3 of these face to face with the groups listed below. The questions asked included: Can you think of any technology you currently use to help with your health and wellbeing? What are the procs/cons of using technology? What technology would be useful to you? What matters most?

- Age UK
- Newton Community Centre
- Senior Citizens Luncheon Club

We ran a paid promotion asking on Facebook 'What do you think of Technology in healthcare?' including a link to our online form asking 'What one thing would you change when it comes to technology and healthcare' (as shown below).

The NHS is changing and your local services need to hear from you!
With growing pressure on the NHS, changes are needed to make sure everybody gets the support they need. The NHS has produced a <u>Long Term Plan</u> , setting out all the things it wants health services to do better for people across the country. Now your local NHS needs to hear from you!
Digital technology is a key part of this plan, for example making it easier for people to access to support closer to home via technology, so we are asking questions about the role of technology. There are no right or wrong answers, we want to know about your thoughts and experiences and what is important to you when it comes to technology in healthcare. This could be do with any aspect of health care; making appointments, viewing your records, monitering a long term condition, and so on.
Click <u>here</u> to find out more about this project
What do you think of digital technology in Healthcare?
What one thing would you change to improve your experience when it comes to technology and healthcare?
I give consent for Healthwatch Warwickshire to store and use this information *
SUBMIT

Summaries from the notes taken for all activities were written up, including quotes from participants of the Coventry Focus Groups.



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