

NHS Long Term Plan

Shropshire, Telford &

Wrekin

Engagement report

whot
would you do?
It's your NHS. Have your say.

March - May 2019

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Sir Neil McKay

Independent Chair

Shropshire, Telford & Wrekin
Sustainability and
Transformation Partnership
(STP).

“I would like to thank Healthwatch Shropshire and Healthwatch Telford & Wrekin colleagues on producing this important report, which has reached many different people across Shropshire, Telford & Wrekin.

As an STP we understand the importance of developing our health and care services based on the views of our local population, alongside the evidence on population health. It is interesting to note that people said they wanted: ‘A person-centred approach to our care,’ and this is central to all the work we are doing. People are at the heart of everything we do and by delivering joined up services in both the acute and community settings we can give everyone the best start in life, creating healthier communities and helping people to age well.

Together with the views of our partners, clinicians, staff and service users we can identify what is working well, what can be improved and what is important to them. This will enable us to plan, design and deliver health and social care services that are right for our local population of Shropshire, Telford & Wrekin.”

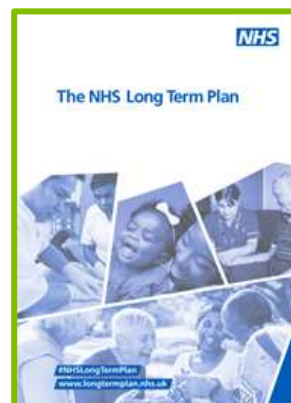
A handwritten signature in black ink, appearing to read 'Sir Neil McKay', written in a cursive style.

Sir Neil McKay

Executive summary

NHS England published ‘The NHS Long Term Plan’ in January 2019. The aim of the plan is to take ‘three big truths’ as its starting point:

- ‘There’s been pride in our Health Service’s enduring success, and in the shared social commitment it represents.
- There’s been concern - about funding, staffing, increasing inequalities and pressures from a growing and ageing population.
- But there’s also been optimism - about the possibilities for continuing medical advance and better outcomes of care.’¹



It sets out some priorities for the future, including:

- Improving how the NHS works so that people can get help more easily and closer to home
- Helping more people to stay well
- Making care better (e.g. for people with cancer, mental health, dementia, lung and heart diseases and learning disabilities such as autism)
- Investing more money in technology

Early 2019, NHS England asked all local Healthwatch to give people in their community the opportunity to have their say on how the national plan is delivered locally, so that their views can feed into the development of local NHS plans.

Local Healthwatch were asked to work within their Sustainability & Transformation Partnership (STP) area. In Shropshire the STP is made up of health and care commissioners and providers from across the Shropshire and Telford & Wrekin local authority areas, so it includes both Councils, both Clinical Commissioning Groups, all the hospital Trusts and West Midlands Ambulance Service.

In the Shropshire, Telford & Wrekin STP area, Healthwatch Shropshire and Healthwatch Telford & Wrekin have worked together to complete this work. Healthwatch Shropshire has acted as co-ordinating Healthwatch and led on this report. Both Healthwatch have worked with the STP to agree our local priorities and approach to gathering people’s views. The STP have told us that what people have told us will ‘inform the development of the NHS local long term plan for Shropshire, Telford & Wrekin’ and help them to make ‘real improvements to services and outcomes for patients across Shropshire’.

Our approach to public engagement in Shropshire, Telford & Wrekin

Healthwatch Shropshire, Healthwatch Telford & Wrekin and the Shropshire, Telford & Wrekin STP agreed that we would use a variety of methods to gather people’s views. We wanted to give people as many ways as possible to answer the question - ‘What would you do?’, while also giving them the chance to share their current experiences of health and care services and voice their thoughts on how these services could be improved. We had to consider the fact that we

¹ www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf

had a short period of time to complete this public engagement (March to May 2019) because the STP has to produce the local plan by the Autumn.

We chose to:

- Use two questionnaire’s designed by Healthwatch England; one focusing on the main priorities of the NHS Long Term Plan and the other focusing on specific health conditions
- Hold two public events; one in Shropshire and one in Telford & Wrekin, asking the broader question ‘What would you do?’
- Run focus groups across the county with people with dementia and their carers and adults with learning disability (and autism) and their carers

Summary of findings

1. Questionnaires

Questionnaire 1 - General experiences of health and social care

167 people in Shropshire and 116 people in Telford & Wrekin completed this questionnaire (Total 283)

People were given groups of statements that described the measures that would support four areas of their lives and they were asked to choose the most important.

The results were:

1. **Living a healthy life** - “Access to the help and treatment I need when I want it”

The detailed responses highlighted what people felt could help them to live a healthy life, including:

- Quicker / more timely access to treatment and services
- Help to make the right lifestyle choices, including access to physical activity
- Appropriate advice and support
- Improved communication, including trustworthy and reliable information
- Access to resources, training and research for staff

2. **Being able to manage and choose the support I need** - “Choosing the right treatment is a joint decision between me and the relevant health and care professional”

In the detailed responses people called for:

- Professionals to take a person-centred approach that involved them in decision making
- Better communication and standards of information that is reliable and timely
- Local services that meet local needs
- Increased resources, including more staff and specialist staff
- Easier access, e.g. to GPs, other health professionals and services (appointments)



3. **The help I need to keep my independence and stay healthy as I get older** - “I want to be able to stay in my own home for as long as it is safe to do so”

Detailed responses highlighted the need for:

- More financial support and practical aids, such as independent living aids
- More support including support for family members
- Support to stay at home and being helped to make real choices
- Support to choose what happens at end of life
- Better transport, including public transport

4. **How you interact with your local NHS** - “I can talk to my doctor or other health care professional wherever I am”

In particular people identified:

- The need for better access to GPs including more time to speak to GPs and seeing the same GP
- The role of technology while also recognising that not everyone has access to a computer/mobile phone or can/wants to use it in this way
- The need for staff and people using services to have access to relevant and reliable information, education and research
- The need for more staff and specialist services
- The need for improved communication between services, including access to shared records

When the importance given to all 25 statements were considered, it was possible to rank them in order of importance.

The **top 10 statements** from all respondents for the Shropshire, Telford & Wrekin STP were:

1. “Professionals that listen to me when I speak to them about my concerns”
2. “Access to the help and treatment I need when I want it”
3. “I want to be able to stay in my own home for as long as is it is safe to do so”
4. “I want my family and me to feel supported at the end of life”
5. “Choosing the right treatment is a joint decision between me and the relevant health and care professional”
6. “I want there to be convenient ways for me to travel to health and care services when I need to”
7. “Easy access to the information I need to help me make decisions about my health and care”
8. “Having the knowledge to help me to do what I can to prevent ill health”
9. “Communications are timely”
10. “I have to consider my options and make choices that are right for me”

The top four statements were the same for people who reported having a long-term condition. The others appeared in a different order, apart from the final statement (statement 10). In the ranking for people with a long-term condition, the final statement was not in the top 10 and was replaced with “For every interaction with health and care services to count; my time is valued”.

Questionnaire 2 - Long term conditions

77 people from Shropshire and 88 people from Telford & Wrekin completed this questionnaire (Total 165)

In this questionnaire people were asked about:

- Their overall experience of getting help
- The impact of having more than one condition at a time on seeking support
- **Waiting times**, including how long people had to wait to get a diagnosis, between assessment/diagnosis and treatment and between initial assessment and seeing a specialist
- **Access to ongoing care and support**
- **Communication** and whether it was timely and consistent from all services they had come into contact with
- **Transport and travel**, including methods of transport and how long people are prepared to travel for to receive quick and accurate diagnosis and specialist treatment or support

As expected, we heard from people who had a range of experiences of getting help across the STP.

Main findings:

Getting help and communication

- The groups that reported the poorest experiences of getting help were those people who had long-term conditions such as arthritis and diabetes, people with mental health difficulties and people with heart and lung disease.
- The majority of respondents from these three groups also reported feeling that they had not received timely and consistent information about their condition from all services.
- People with cancer seemed to be the happiest with the communication that they had received.

Impact of having more than one condition

- 82 people across these groups had more than one condition and 51 (62%) said they thought that it made seeking support 'harder'.
- The groups that felt it made it hardest were adults with learning disabilities (86%), people with mental health difficulties (71%) and people with autism (67%).
- Only six people (7%) thought it made it 'easier'. Three had a long-term condition, two had mental health difficulties and one had cancer.

Waiting times

- None of the nine respondent with dementia described the amount of time they had to wait to receive their initial diagnosis/assessment, then receive treatment and then see the specialist as 'fast' or 'very fast'. Five did not answer the question about how long it had taken between receiving a diagnosis and seeing a specialist.
- None of the respondents with a learning disability or autism described the amount of time they had had to wait to see a specialist as 'fast' or 'very fast'. However depending on their diagnosis and when this had happened they might not have remembered seeing a specialist (e.g. if they were diagnosed as a child).

What would you do?

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- The majority of people with a mental health difficulty described the waiting times as ‘very slow’ or ‘slow’ at each of the three stages. For example, 22 people (65%) said that the time they had to wait to receive an initial assessment or diagnosis was ‘very slow’ (10) or ‘slow’ (12).
- The only condition where the majority of people described these waiting times as ‘fast’ or ‘very fast’ was cancer.

Access to ongoing care and support

- A recurring theme from people with a variety of long-term conditions including Autism, Mental Health challenges and cancer was improved access to the most appropriate specialist service at each stage of diagnosis and treatment.
- Direct access to specialist staff includes telephone access for those on mental health waiting lists, specialist nurse support for neurological conditions and follow up from clinical cancer nurses.

Transport and travel

- The majority of respondents from all groups told us they would be prepared to travel up to an hour to receive a quick and accurate diagnosis or to receive specialist treatment and support. This is likely to have been linked to access to transport, for example, the majority of respondents reported having their own car or access to somebody else’s.
- The groups where a significant number of respondents said they would be prepared to travel for between 1 - 2 hours or over 2 hours to get a quick diagnosis and receive specialist treatment and support were those people who had a long-term condition such as arthritis and people with a mental health problem. Both of these groups also reported slow waiting times for diagnosis and treatment.

2. Public events - ‘What would you do?’

A total of 38 people attended the two public events, 19 joined us at Meeting Point House in Telford and 19 came to The Trinity Centre in Shrewsbury.



The three questions we asked were:

- How can you be supported to live a healthier life?
- What can services do to provide you with better care and support?
- What would make it easier for you to take control of your health and wellbeing?

People told us that a number of things are important and should be priorities:

1. Access and timely intervention e.g.

- local services that people know about, that are available when people need them (including 24 hour) and that they can get to easily, including services that can help people to live healthy lives such as affordable gyms and social groups
- services that have time to spend with people, where people can see the same professional/s
- Consideration for the challenges people face regarding travel to services, including anxiety, timing of appointments, etc.

2. **Tackling isolation and loneliness e.g.**
 - Making sure socially isolated people know what support is available to them and how to access it, including homeless people and people who do not have a named GP or relationship with services
3. **Consistent and reliable information and education for all ages² e.g.**
 - Reducing confusion by giving clear and consistent information that can be trusted, including information about services such as available appointments
 - Giving people a single point of contact to improve consistency, including appropriate signposting and offering information and advice (e.g. advice about medication)
 - Working with education to ensure the right messages are given from an early age about healthy lifestyles, care and compassion, emotional intelligence, resilience and how to use services
4. **Services working together, including information sharing and a flexible approach to working e.g.**
 - Ensuring staff know what other services are out there and talking to each other, improved referral processes, social services and the NHS working together
 - Building trusted networks to help organisation work together and share knowledge and experience (including with organisations like Parish Councils)
 - Having shared digital records, including care plans
5. **Building strong communities and investment in local people**
 - Supporting and promoting local groups to enable and encourage people to get together, e.g. walking groups, dementia groups
 - Raising awareness (conditions and services available) across all ages, e.g. awareness of mental health to reduce stigma and enable people to ask for help sooner
 - Addressing needs, including housing, food banks and public transport, e.g. housing that works for people as they age or their needs change, easy access to living aids to help people stay at home for as long as possible
 - Recognising the role of needs of carers
6. **Individualised care, including using a range of communication methods, e.g.**
 - Using the most appropriate form of communication for each individual in order to share information quickly, e.g. text or email instead of letters
 - Making sure people understand the information they are given
 - Involving people and helping them to make informed decisions

3. Focus groups

People with dementia and their carers

Across Shropshire, Telford & Wrekin we ran a total of 16 focus groups and spoke to 48 people with dementia and 49 carers.

People told us about:

- Their experiences around getting a diagnosis, including the information they were given



² The issues around Accessible Information were explored in the HWS '[NHS Accessible Information Standard in GP Practices](#)' report

- The support they have received post-diagnosis, including from GPs and the Memory Service
- Their experiences of being in hospital
- The role of carers and the importance of support groups and social connections

Our findings show that what matters most to people in Shropshire, Telford & Wrekin who are living with Dementia and their carers is:

1. Receiving timely, on-going, reliable information, including:

- Information about the diagnosis and on-going support available, e.g. for incontinence
- Information about local support / social groups (either Dementia friendly or specifically for those with dementia and their carers), help and advice about using public transport
- Practical information, e.g. wills and probate, mental capacity and Power of Attorney, driving and the DVLA

2. Support for carers, including:

- Weekly, planned breaks from caring responsibilities while their loved one is cared for in a safe environment, e.g. Day centre, 1:1 care at home
- Having their concerns heard and responded to, e.g. around diagnosis, the need for help
- Support for their own emotional health and wellbeing, e.g. emotional support and reassurance that what they are doing is the best for their loved one

3. Access to and on-going support for the person with Dementia and their carer, including:

- Seeing the same GP
- Priority GP appointments, longer appointments, in particular for emergencies
- Crisis support out of hours and at weekends
- Help to link in with other services and information about the support available, possibly from a named link worker
- A consistent approach to identifying, recording, flagging and sharing the needs of people with dementia and their carers to prevent repetition, in line with the NHS Accessible Information Standard
- Consistent Memory Service provision across the County
- Effective and consistent use of Care Plans, 'This is me' and the Butterfly symbol

These findings supported many of the issues highlighted in a survey completed by Dementia Action Alliance (DAA) Autumn 2018.³

People with a learning disability (including autism) and their carers

Taking Part helped us to engage with 58 people, 48 in focus groups and ten in one to one sessions. Of the 48 people in the groups, 42 had a learning disability, four had autism and two had both a learning disability and autism. Eighteen people also had other long-term conditions.

³ Dementia in Shropshire and Telford and Wrekin <https://drive.google.com/file/d/1FZrzKCmWYD-92JLMY1ZFxvel-I2wVDea/view>

Our findings show that what matters most to people in Shropshire, Telford & Wrekin who have learning disabilities and autism is:

1. **Clear communication with health workers**, including easy read information
2. **Consistency of health care professional** e.g. the same doctor
 - This was highlighted by all members of the focus groups (those with learning disabilities and those with autism). However, those with autism who filled out the second questionnaire indicated that it was less of an important factor in the various stages of their support
3. **Compassion**, understand that I am a person not a ‘condition’ and do not let my disability overshadow other potential conditions.
4. **Easy access to appointments**
 - A theme raised by respondents with autism indicated the importance of seeing a specialist at the initial stages of assessment.
5. **Carers who I know and I can trust**
6. **Timely, on-going, reliable information and advice for carers**
7. **The importance of the Annual Health Check**

Key messages for the Shropshire, Telford & Wrekin Sustainability and Transformation Partnership

To achieve the following priorities people told us they want the NHS to:

1. **Improving how the NHS works so that people can get help more easily and closer to home**
 - Give us access to help and treatment when and where we want it
 - Give us easier and quicker access to GPs
 - Have enough staff, including specialist staff, to help us get a diagnosis and receive treatment more quickly
 - Provide us with appropriate, clear and timely information and advice, e.g. from a single point of contact
 - Let us know what support is available so we understand our options, including support from the community (e.g. advocacy support and support/social groups)
 - Help us to stay in our own home for as long as it is safe to do so, including access to financial support, practical support and independent living aids
 - Help us when we have to travel, including giving us information about transport and convenient ways to travel. (Remember some of us might be willing and able to travel further if it means getting a quicker appointment, diagnosis and treatment)
 - Consider the timing of appointments so you take into account how we are going to get there and remember that some of us need to be supported to attend appointments, e.g. due to a health condition, including anxiety. Remember some of us might be willing and able to travel further/longer if it means getting a quicker appointment
 - Give staff access to resources, training and research so they understand our needs, the full range of services and support available to us and can make appropriate referrals (e.g. to other parts of the NHS, social care, community support)
 - Make sure services work more closely together, including sharing information and communicating better to avoid confusion and misunderstanding

2. Helping more people to stay well

- Make sure the information you give us is reliable and consistent and we can easily understand it (including following the NHS Accessible Information Standard), e.g. about how we can stay well and what to do when we first feel unwell
- Help us to make the right decisions that will keep us fit and healthy longer, including helping us to get good food, use gyms and have health checks (e.g. Annual Health Checks for people with learning disabilities)
- Contact those of us who are socially isolated and vulnerable to make sure we have equal access to information, advice and services

3. Making care better

- Make sure all staff take a person-centred approach to our care, that takes into account our individual needs and those of our family/carers, including information and support to make real choices (e.g. about end of life)
- Treat us all with compassion and see past a pre-existing condition to make sure other health problems are not missed, e.g. when treating those of us with a mental health condition or learning disability/autism
- Provide us with consistency to build our trust, including consistency of staff, information and advice, e.g. known carers, use of 'This is me' and the Butterfly symbol for people with a dementia diagnosis/confusion across services and departments
- Make sure our care plans are created with us and our family/carers and that they are useful and meaningful

4. Investing more money in technology

- Use shared digital records, including care plans, that can be accessed by all professionals involved in our care
- Support us to use technology but also recognise that we don't all have access to a computer or smart phone and we can't all use technology in this way (some of us don't want to)

Background

Purpose

The Shropshire, Telford and Wrekin Sustainability and Transformation Partnership (STP) is one of 44 STPs across England. It is made up of health and care commissioners and providers including:

- Shropshire Council
- Telford & Wrekin Council
- NHS Shropshire Clinical Commissioning Group
- NHS Telford & Wrekin Clinical Commissioning Group
- Shrewsbury & Telford Hospital NHS Trust
- Robert Jones & Agnes Hunt Orthopaedic Hospital NHS Foundation Trust
- Midlands Partnership NHS Foundation Trust
- Shropshire Community Health NHS Trust
- West Midlands Ambulance Service NHS Foundation Trust

The role of the STP is to:

- Encourage health and care organisations to work more closely together to improve outcomes and care for local people
- Reduce pressures on services
- Make best uses of financial resources

The NHS faces a growing demand for its services, with growing pressure nationally from an ageing population, more people living with long-term conditions and lifestyle choices affecting people's health. Change is needed to make sure everyone gets the support they need so in January 2019 NHS England published its Long Term Plan and every STP has been asked to produce a local plan for their area.

The Long Term Plan is all about:

- Making sure everyone gets the best start in life
- Delivering world-class care for major health problems
- Supporting people to age well
- Ensuring NHS staff get the support they need
- Digitally enabled care
- Effective use of resources

Priorities include:

- Improving how the NHS works so that people can get help more easily and closer to home (e.g. being able to speak to your GP on your computer or smart phone)
- Helping more people to stay well (e.g. helping people to stay a healthy weight or stop smoking)
- Making care better - the NHS wants to get even better at looking after people with cancer, mental health, dementia, lung and heart disease and learning disabilities such as autism
- Investing more money in technology so that everyone is able to access services using their phone or computer, and so that health professionals can make better, faster decisions

What would you do?

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People told Healthwatch that they wanted to be involved and take more control of their health and care. In January 2019, Healthwatch England asked all local Healthwatch⁴ to work within their STP areas to find out what local people think about the NHS Long Term Plan and reach out to specific communities. The STP (NHS) is expected to undertake its own public engagement work. The activity of Healthwatch aims to complement and support this work.

In our STP area Healthwatch Shropshire and Healthwatch Telford and Wrekin met with the STP to agree our local priorities and how Healthwatch would engage with people across the county to get their views.

The Shropshire, Telford and Wrekin STP priorities for 2019/20 are:

- Urgent and emergency care
- Mental health
- Out of hospital care

We agreed to do general engagement around the priorities of the NHS Long Term Plan and focus on mental health because work is already underway in Shropshire, Telford & Wrekin looking at urgent / emergency care and out of hospital care. The STP includes dementia and learning disability under 'mental health' and it was agreed that we would do more focused engagement with these groups to make sure they could contribute to the discussions in a way that met their needs, e.g. face-to-face, informal conversations. We planned to get responses to three key questions:

- How can you be supported to live a healthier life?
- What can services do to provide you with better care and support?
- What would make it easier for you to take control of your health and wellbeing?

Objectives - The challenge

The challenge for the STP and Healthwatch Shropshire and Healthwatch Telford & Wrekin was to reach a diverse population living in both urban and very rural areas. We wanted to gather the views from as many people as possible that recognised the wide variation in personal experiences of accessing and using health and social care services across the county so decided to use a range of engagement methods.

⁴ All 152 Local Authority areas in England have a Healthwatch

Context: Our population

In 2017, Shropshire had a population of 317,459⁵ and Telford and Wrekin had a population of 175,271⁶.

Shropshire:

- In Shropshire a higher proportion of residents live in rural areas as defined by the 2011 rural urban classification scheme with 0.98 people per hectare compared to 4.24 in England.
- The age profile of Shropshire shows that over 45.1% of residents are aged 50 and over. This is higher than the rate for both England (36.7%) and West Midlands (31.9%) which stands at 36.5%. Life expectancy in Shropshire is above the average for England.
- According to the Index of Multiple Deprivation which separates the county into areas of 1,000 to 3,000 people there are nine areas in Shropshire that fall within the 20% most deprived in England. They are all located within urban areas of the county. Harlescott in Shrewsbury falls within the 10% most deprived areas in England. Other areas of multiple deprivation are in Ludlow and Oswestry.

Telford & Wrekin:

- The population of Telford & Wrekin is 'younger' than the national position, although with the fastest growth being in the 65+ age group the age profile of the borough is now much closer to the national position. Reflective of the population, Telford & Wrekin has a higher proportion of households with dependent children and a lower number of households aged 65+.
- Male life expectancy has increased over the last decade, but has been significantly worse than England average since 2006-08. Female life expectancy has increased, but has been worse than England average since 2008-10.
- The population is becoming more diverse. As well as new migrants a key driver of change has been the younger age structure of BME groups leading to a greater likelihood of them having children.
- A higher proportion of people in Telford & Wrekin report having bad or very bad health than the England rate.
- In 2015, more than a quarter (27%) of the Telford & Wrekin population lived in the 20% most deprived areas nationally, an increase on 24% in 2010.

Engagement methods:

In the Shropshire, Telford and Wrekin STP area we agreed to use the following methods to engage with people:

- Healthwatch England Questionnaires (primarily on-line and paper)
- Focus groups / workshops / 1:1s
- Public events
- General public engagement (e.g. talks, stands)

⁵ All data from 'Shropshire Council Key Facts & Figures Shropshire Data 2017/18'

⁶ All data from 'Facts and Figures - Key Messages for Telford & Wrekin December 2017'

- Press releases
- Newsletter and email publicity
- Social media (including Twitter, Facebook, Instagram)
- Looking at existing evidence (including previous Healthwatch Reports and other reports by local organisations that offer views relevant to the long term plan)

External factors:

At the time of doing this piece of work, local Council elections were taking place in Telford & Wrekin. According to the Local Government Association:

‘The term ‘purdah’ [is used] across central and local government to describe the period of time immediately before elections or referendums when specific restrictions on communications activity are in place.’ www.local.gov.uk

This had a direct impact on Healthwatch Telford & Wrekin’s plans for engagement, for example Telford & Wrekin Council declined to share any press releases, social media posts or posters to people on their correspondence lists. Healthwatch Telford and Wrekin were also told by several venues and organisations that they could not promote the questionnaires or their public event, or hold a focus group, e.g. public libraries. Even local supermarkets refused to promote any materials.

Next Steps

The STP have told Healthwatch Shropshire and Healthwatch Telford & Wrekin that the views gathered and shared in this report will:

- Inform the development of the local long term plan for Shropshire, Telford & Wrekin
- Turn the national ambitions contained in the NHS Long Term Plan into real improvements to services and outcomes for patients across Shropshire

Following this engagement and the publication of this report, both Healthwatch will continue to share any results from our wider engagement, including relevant comments and reports with the STP so that the views of people in Shropshire and Telford & Wrekin continue to be taken into account as the long term plan is implemented.

What we did

Across the Shropshire, Telford & Wrekin STP area we heard the views of 641 people. Healthwatch Shropshire heard from 376 people (0.12% of the population of Shropshire) and Healthwatch Telford & Wrekin heard from 265 people (0.15% of the population of Telford & Wrekin)

Details of our engagement activities:

1. Questionnaires

We promoted two questionnaires developed by Healthwatch England to get people’s feedback. The first questionnaire was more general and an opportunity for people to say what they thought

the local NHS should do to make care better for their communities. The second questionnaire was specifically to gather the views of people with long-term conditions, including:

- Cancer
- Heart and lung diseases
- Mental Health
- Dementia
- Learning disability
- Autism
- Long-term condition e.g. diabetes, arthritis

Responses:

1. The **general questionnaire** was filled out by 167 people from Shropshire and 116 from Telford & Wrekin. Full results are in [Appendix 1](#)
2. The **long-term condition (LTC) questionnaire** was filled out by 77 people from Shropshire and 88 from Telford & Wrekin. Full results are in [Appendix 2](#)

Respondents (order in which these conditions appear in the report)

Condition	Shropshire	Telford & Wrekin	Total*
Dementia	4	5	9
Learning disabilities	10	9	19
Autism	3	8	11
Long term condition (e.g. diabetes arthritis)	29	33	62
Mental health	19	17	36
Cancer	8	9	17
Heart and lung disease	4	7	11

**Please note: Not all respondents answered all questions*

2. Focus groups

We ran focus groups / small groups discussions or 1:1s with people with dementia and their carers and people with Learning Disabilities and their carers. This gave us the opportunity to speak to people in a way that could support their understanding and ensure they could communicate their views in a way that worked for them.

Dementia focus groups

Shropshire Groups	People living with Dementia	Carers	Area
Alzheimer's Peer Support Group	0	9	Shrewsbury
Dementia Football	4	3	Highley
Alzheimer's Dementia Café	5	6	Ludlow
Market Drayton Festival of Wellbeing	3	1	Market Drayton
Alzheimer's Peer Support Group	0	3	Church Stretton
Rural Community Council (RCC) Care & Share Group	6	6	Church Stretton
DEEP ⁷ Group	5	0	Shrewsbury
Alzheimer's Dementia Café	3	4	Oswestry
Alzheimer's Dementia Focus Group	4	0	Bridgnorth
Memory Service & Age UK group	5	8	Bridgnorth
Total	35	40	
Telford & Wrekin Groups			
Age UK	4	2	Ketley Bank
Age UK	2	2	Dawley
Carers Centres (combined)	1	2	Hadley, Leegomery, Newport
Age UK	1	0	Wellington
Alzheimer's Society	4	0	Telford
Rose Manor family meetings (x2)	1	3	Ketley
Total	13	9	

⁷ DEEP stands for the Dementia Engagement and Empowerment Project - it is the UK network of dementia voices

The feedback is summarised on page 39. Full details of the feedback are in [Appendix 3](#).

Focus groups with adults with learning disabilities and autism

We worked in partnership with *Taking Part*, an Independent Service for people with Health and Social Care needs in Shropshire including Telford & Wrekin, to engage with adults with learning disabilities and autism. Taking Part's existing relationship with this group is based on trust and they were able to explain the value of their involvement and encourage them to share their views.

The feedback from the groups is summarised on page 40. Full details of the feedback are in [Appendix 4](#)

Taking Part spoke to 58 people: 28 people in groups in Shropshire and 20 in Telford, they also spoke to 10 people in Shropshire on a one to one basis.

Note about other conditions

Healthwatch Shropshire and Telford & Wrekin did not have the time or capacity to complete any face-to-face engagement with people about the other conditions listed on p.6 as part of this piece of work, e.g. cancer, heart and lung disease, diabetes, long-term conditions such as arthritis and diabetes, or wider mental health conditions.

A breakdown of the responses people with these conditions gave when completing the long-term condition questionnaire is included in this report from p. 66

3. Public events - 'What would you do?'

We ran two **public events**, one in Shropshire and one in Telford and Wrekin.

The aim of these events was to give people another way to respond to the three key questions and share their views, particularly if they did not choose to complete the questionnaires. It also allowed us to give people information about the work already being done in the county that illustrate the ambitions of the NHS long term plan, e.g. Social Prescribing and Care Closer to Home (Shropshire), Neighbourhoods (Telford & Wrekin).

- Nineteen people attended a public event, led by Healthwatch Telford & Wrekin (HWT&W) and supported by Healthwatch Shropshire (HWS), at Meeting Point House, Telford Town Centre.
- Nineteen people also attended a mirror event, led by HWS and supported by HWT&W, at The Trinity Centre in Meole Brace, Shrewsbury.

Full details of the feedback are in [Appendix 5](#).

Please note: It is not clear how many people completed the questionnaires and then also shared their views with us at a focus group or public event.

What matters most to people in Shropshire, Telford & Wrekin

General experiences of health and care services

In Questionnaire 1, people were asked to rate the importance of 25 suggested measures that helped to support the following four areas:

1. Living a healthy life
2. Being able to manage and choose the support I need
3. The help I need to keep my independence and stay healthy as I get older
4. How you interact with your local NHS

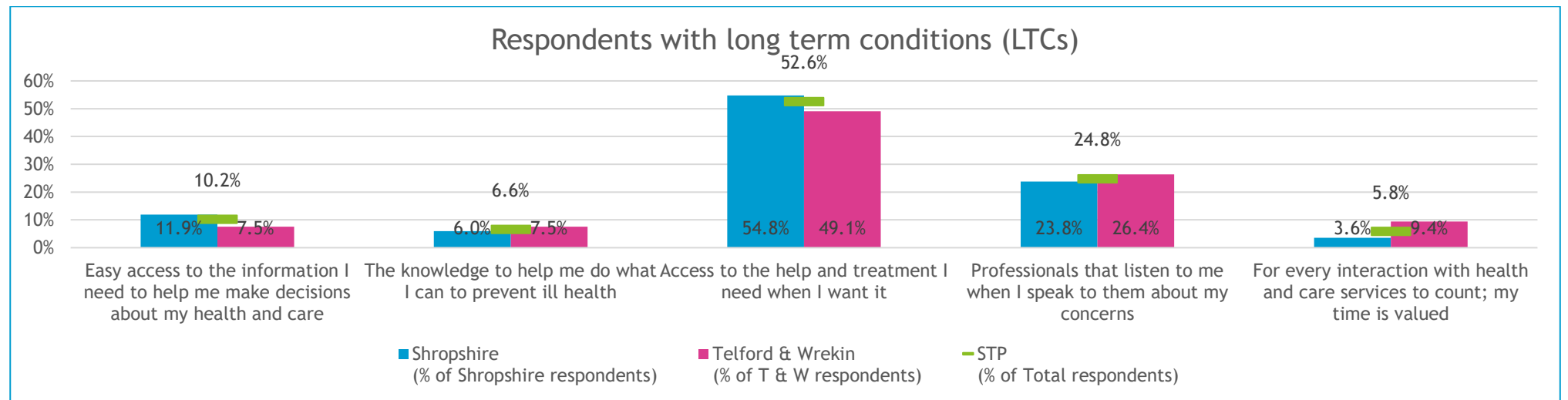
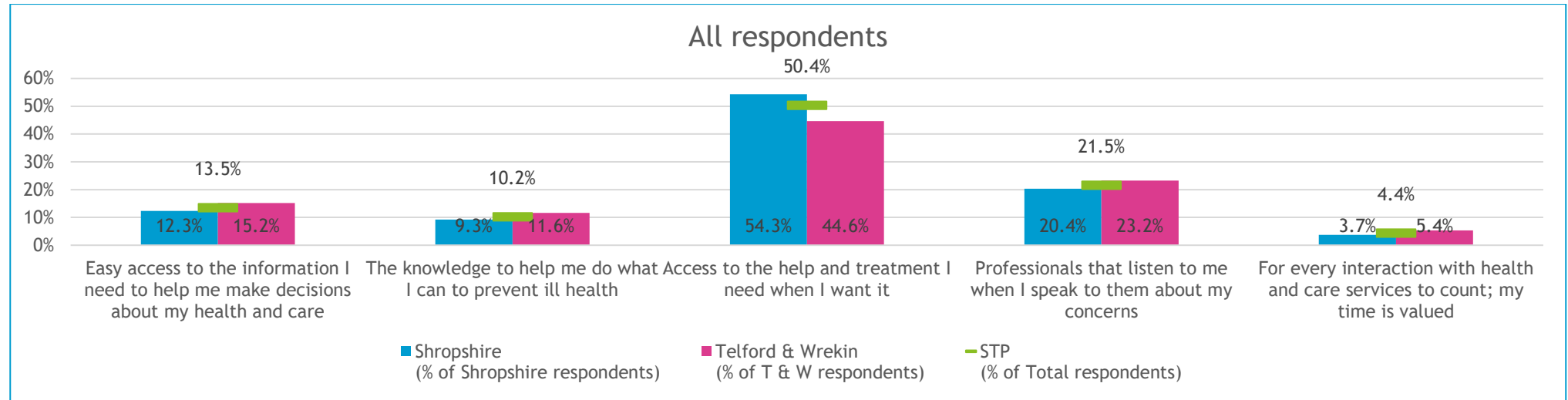
This questionnaire was completed by 167 people from Shropshire and 116 from Telford & Wrekin (Total 283).

All twenty-five measures were deemed overwhelmingly important or very important. Overall importance rating of all statements:

- **Very important** 58.77%
- **Important** 27.96%
- *Neutral (or left blank)* 12.72%
- Not important 0.49%
- Not very Important 0.07%

Respondents were then asked to choose the most important measure from each of the four areas.

1. Having what I need to live a healthy life



What would you do?

Most important to live a healthy life:

“Access to the help and treatment I need when I want it”

When the responses from people with long-term conditions (LTCs) and people without LTCs were analysed separately the two top most important measures were the same as the overall results.

🟢 If there were one more thing that would help you live a healthy life, what would it be?

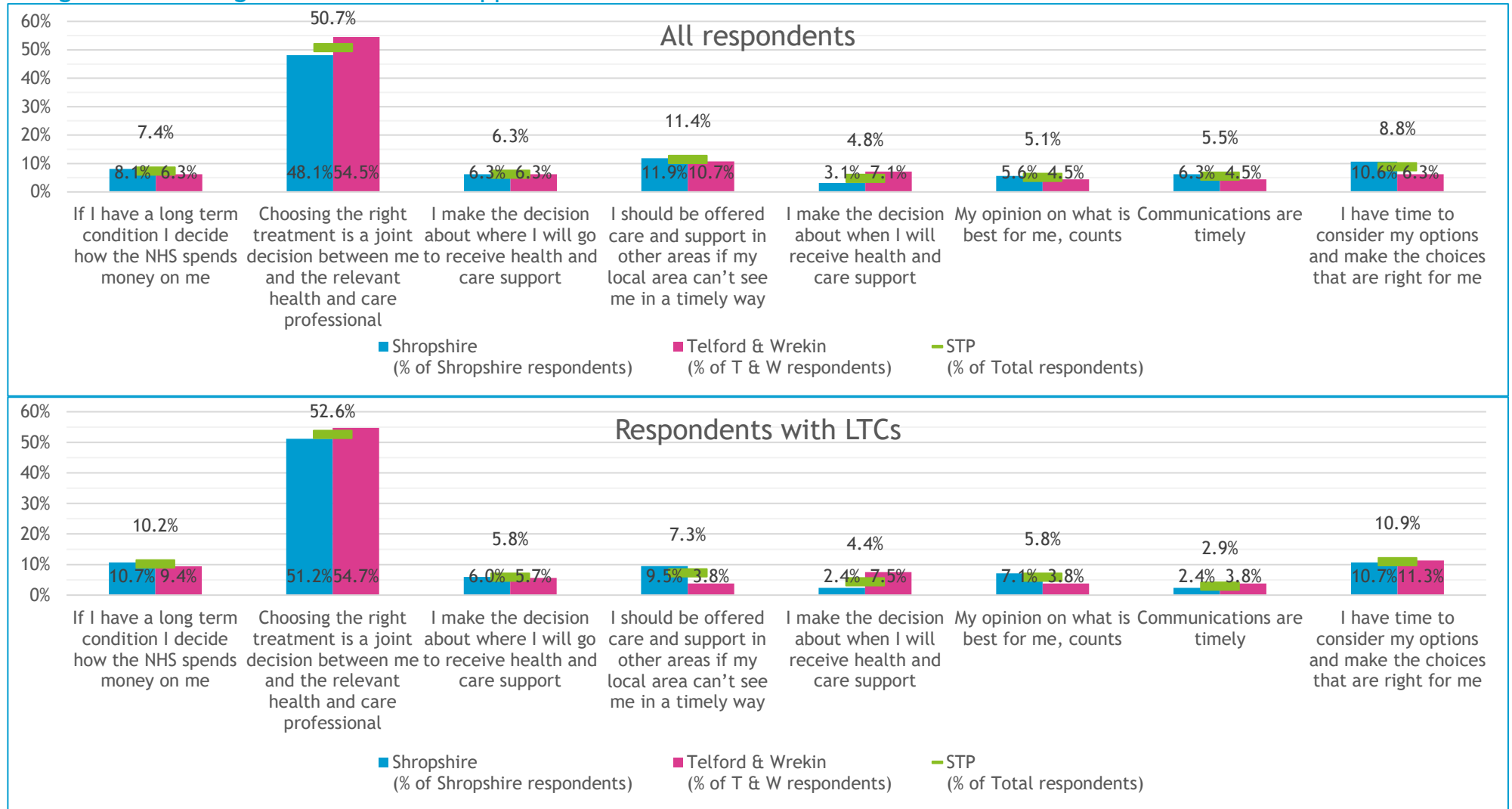
In the free text box, people told us that the following things would help them to live a healthy life:

Summary of top five things people thought would help in order of importance (number of respondents):

1. **Access to treatment and services** (Shropshire 34, Telford & Wrekin 12), e.g. “short waiting times” and “access to help and treatment when I need it”
2. **Help to make the right lifestyle choices** (Shropshire 16, Telford & Wrekin 10), over half referred to physical activity, e.g. “cheaper access to sport facilities”
3. **Advice and support** (Shropshire 12, Telford & Wrekin 12), e.g. information about “what support is available after diagnosis”, “supporting me when I am on the right track”
4. **Improved communication** (Shropshire 13, Telford & Wrekin 5) e.g. “knowing how to differentiate between the misinformation fed to me by the media...”, “better communication about preventative tasks and health checks”
5. **Staff access to resources, training and research** (Shropshire 10, Telford & Wrekin 4) e.g. “ understanding from all health professionals of mental health”

For additional information see [Appendix 1](#)

2. Being able to manage and choose the support I need



What would you do?

Most important in being able to manage and choose the support I need:

“Choosing the right treatment is a joint decision between me and the relevant health and care professional”

When the responses from people with LTCs and people without LTCs were analysed separately the most important measure, choosing the right treatment being a joint decision, is the same for both groups. However those with a LTC felt that the next most important measure was ‘deciding how the NHS spends money on me’ whereas those without a LTC felt that the next most important was being offered care in other areas to achieve timely treatment.

● If there was one more thing that would help you manage and choose how the NHS support you, what would it be?

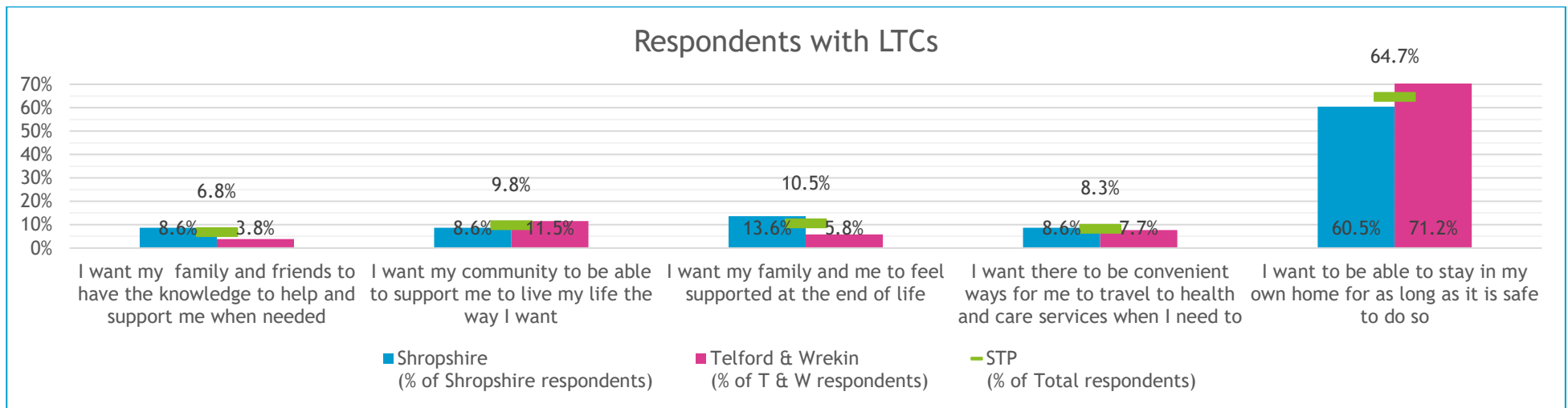
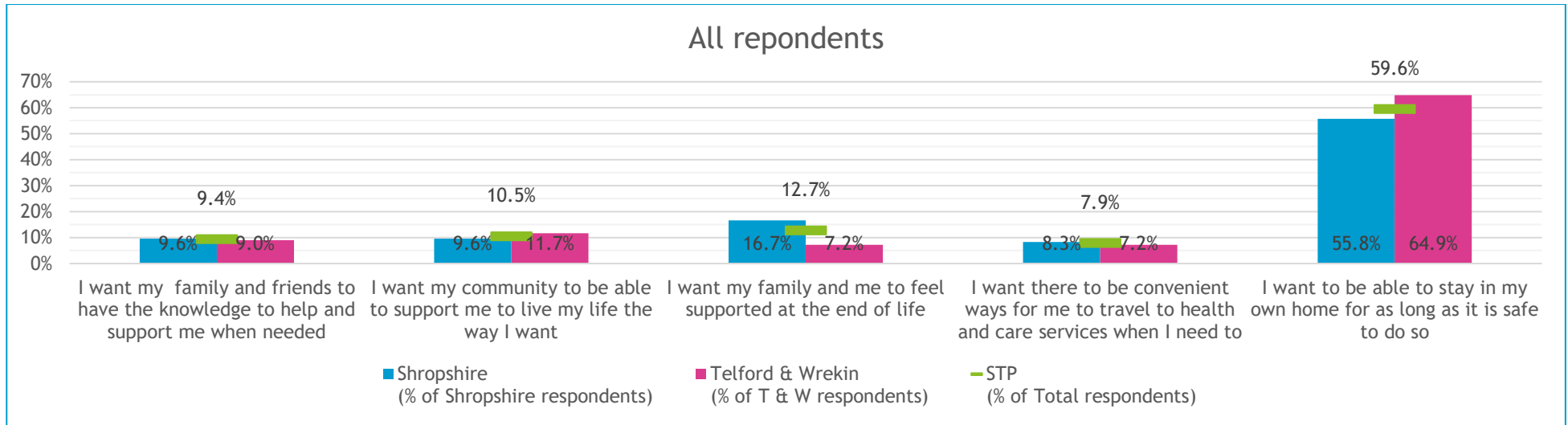
In the free text box, people told us that the following things would help them to manage and choose how the NHS support them:

Summary of top five things people thought would help in order of importance (number of respondents):

1. **Professional taking a person-centred approach** (Shropshire 17, Telford & Wrekin 14), e.g. being “involved in decision making”, “listen to me...”, “professionals to have the time”, being given information to make an informed choice, access to the right professionals
2. **Better communication and information** (Shropshire 18, Telford & Wrekin 11) e.g. reliable, efficient and timely information including information about service performance
3. **Local services to meet local needs** (Shropshire 8, Telford & Wrekin 7) a number of people mentioned Future Fit and planned changes to urgent and emergency care, “Don’t close accident and emergency in Telford”, “it would be beneficial if local commissioners acted on local needs...”
4. **Increased resources such as staffing** (Shropshire 13, Telford & Wrekin 1) more than half of these people mentioned staffing, e.g. “network of appropriate support workers”, “more GPs..”, “make sure there are enough specialists”
5. **Easier access to GPs/health professionals/services** (Shropshire 7, Telford & Wrekin 5), e.g. appointments,

For additional information see [Appendix 1](#)

3. The help I need to keep my independence and stay healthy as I get older




What would you do?

Most important in being able to manage and choose the support I need:

“I want to be able to stay in my own home for as long as it is safe to do so”

When the responses from people with LTCs and people without LTCs were analysed separately the two top most important measures were the same as the overall results.

 *If there was one more thing that would help you retain your independence and live healthily for as long as possible, what would it be?*

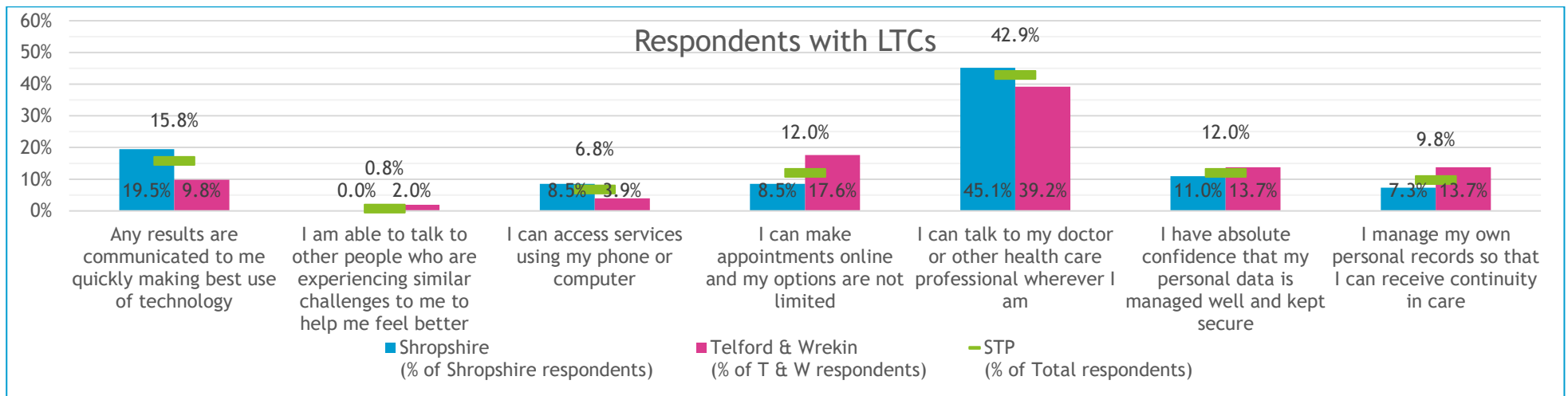
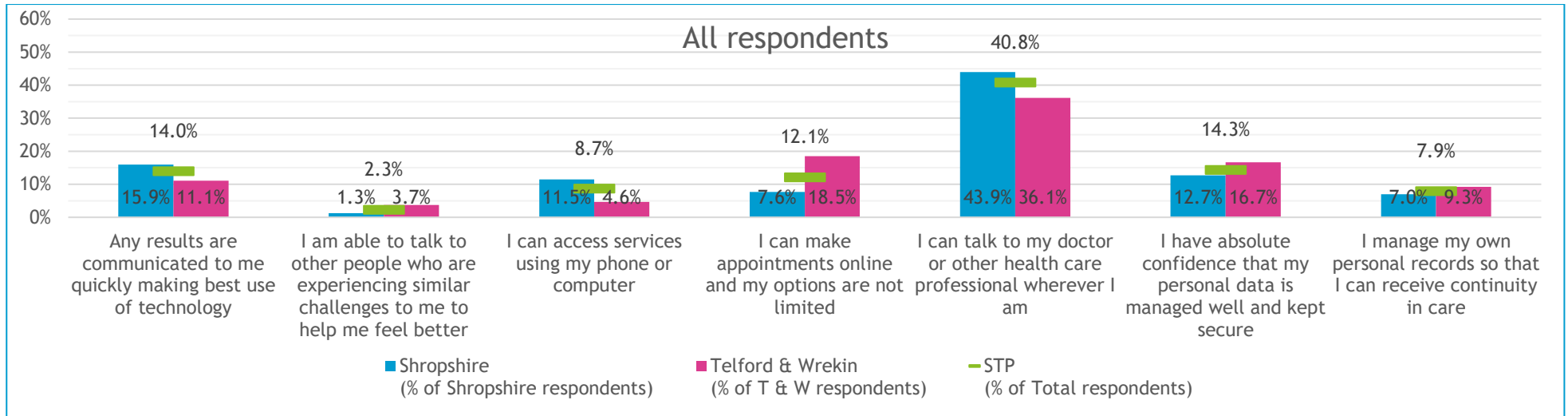
In the free text box, people told us that the following things would help them to retain their independent and live healthily for longer:

Summary of top five things people thought would help in order of importance (number of respondents):

1. **Increased resources including financial support and practical aids** (Shropshire 15, Telford & Wrekin 8), e.g. “easy access to aids and adaptations”, “financial support to adapt my home if necessary”, “investment in community support”
2. **Support** (Shropshire 10, Telford & Wrekin 8) including support for family members
3. **Care at home** (Shropshire 7, Telford & Wrekin 8), e.g. “better community response to home” to be at home as long as possible” and a **person-centred approach** (Shropshire 11, Telford & Wrekin 4) to ensure personal needs are met and people can make “real choices”
4. **End of life care** and having a say so that people have a choice about what happens and “feel supported at end of life (Shropshire 9, Telford & Wrekin 3)
5. **Better transport** (Shropshire 4, Telford & Wrekin 4) including more transport and “better public transport”

For additional information see [Appendix 1](#)

4. How you interact with your local NHS



Most important in being able to manage and choose the support I need:

“I can talk to my doctor or other health care professional wherever I am”

When the responses from people with LTCs and people without LTCs were analysed separately the top most important measure was the same as the overall results.

The second most important measure differed. Those with a LTC prioritised, ‘Any results are communicated to me quickly making the best of technology’ while those without prioritised ‘I have absolute confidence that my personal data is managed well and kept secure’.

● If there was one more thing that you think needs to change to help you to successfully manage your health and care, what would it be?

In the free text box, people told us the thing they thought would need to change to help them to manage their health and care.

Technology was mentioned in a number of ways which proved challenging when analysing the comments. People identified a need for an improved use of IT by services, including shared records, but its limitations for communication with patients was highlighted, in particular those people with limited access to IT or no experience of using it.

Summary of top five things people thought would help in order of importance (number of respondents):

1. **GPs** (Shropshire 10, Telford & Wrekin 16) 69% of the people who highlighted GPs felt better access would be most helpful, including GPs having time to speak to them, reduced waiting times and “having access to the same Doctor...”
2. **Developing technology*** (Shropshire 19, Telford & Wrekin 6) 11 people made negative comments about the current use of technology but also its limitations, e.g. “Elderly people are not always computer literate...”
3. **Access to information, education and research for professionals but also people using services** (Shropshire 9, Telford & Wrekin 8) including an improved understanding of the other services/support available, e.g. “Professionals should acknowledge patients’ support groups...”
4. **Increased staffing and service provision** (Shropshire 9, Telford & Wrekin 5) e.g. “more doctors and nurses”, “the way people access services particularly mental health help...”
5. **Communication and patient records** (Shropshire 13, Telford & Wrekin 5) e.g. “better communication between services and hospital departments”, “All medical records kept on a single data base and available to both patient and medical practitioners...” *This links to developing technology.

For additional information see [Appendix 1](#)

What would you do?

Overall ranking

To gauge relative importance between all 25 measures, the importance given to each individual statement was weighted and amalgamated. Weighting: Very Important = 2, Important = 1, Neutral = 0, Not important = -1, Not important at all = -2

Top 10 statement - All respondents	Shropshire Score	Shropshire Rank	Telford & Wrekin Score	Telford & Wrekin Rank	STP Score	STP Rank
Professionals that listen to me when I speak to them about my concerns	296	1	215	2	511	1
Access to the help and treatment I need when I want it	287	3	216	1	503	2
I want to be able to stay in my own home for as long as it is safe to do so	292	2	206	3	498	3
I want my family and me to feel supported at the end of life	277	4	204	4	481	4
Choosing the right treatment is a joint decision between me and the relevant health and care professional	264	8	200	5	464	5
I want there to be convenient ways for me to travel to health and care services when I need to	270	5	192	6	462	6
Easy access to the information I need to help me make decisions about my health and care	269	6	188	9	457	7
Having the knowledge to help me do what I can to prevent ill health	268	7	182	11	450	8
Communications are timely	257	10	190	7	447	9
I have time to consider my options and make the choices that are right for me	248	12	189	8	437	10

Top 10 statements - Respondents with LTCs	Shropshire Score	Shropshire Rank	Telford & Wrekin Score	Telford & Wrekin Rank	STP Score	STP Rank
Professionals that listen to me when I speak to them about my concerns	159	1	104	1	263	1
Access to the help and treatment I need when I want it	152	3	101	2	253	2
I want to be able to stay in my own home for as long as it is safe to do so	155	2	95	3	250	3
I want my family and me to feel supported at the end of life	147	4	94	4	241	4
Easy access to the information I need to help me make decisions about my health and care	143	5	92	7	235	5
Choosing the right treatment is a joint decision between me and the relevant health and care professional	140	6	94	4	234	6
I want there to be convenient ways for me to travel to health and care services when I need to	139	8	93	6	232	7
Having the knowledge to help me do what I can to prevent ill health	140	6	89	8	229	8
For every interaction with health and care services to count; my time is valued	134	9	86	10	220	9
Communications are timely	132	10	88	9	220	9

Public events - 'What would you do?'

The Healthwatch Telford & Wrekin Event was held at Meeting Point House at Telford Town Centre on 29th April 2019. It was attended by 19 people; nine of these completed the Equality & Diversity Monitoring Form.

The Healthwatch Shropshire Event was held at the Trinity Centre in Shrewsbury on 1st May 2019. It was also attended by 19 people, 11 of these completed the Equality & Diversity Monitoring Form.



	Telford & Wrekin Event (9 responses)	Shropshire Event (11 responses)
Age range	18-24 to 75+	35-44 to 75+
Nationality	9 White British	10 white British, 1 other
Disability	3	4
Conditions	2 long term conditions	2 long term condition, 3 multiple conditions
Carer	4	2
Gender	5 male, 4 female	7 male, 3 female

Full Equality & Diversity Data is listed in [Appendix 5](#)

People attending both events were asked the following key research questions:

- **How can you be supported to live a healthier life?**
 - What is stopping you from living a healthier life
 - What could help you to live a healthier life
 - What could health and social care services do to help you to live a healthier life?
- **What can services do to provide you with better care and support?**
 - What is your experience of care and support now?
 - What small changes would make a difference?
 - In an ideal world, what would services do? (differently, more of)
- **What would make it easier for you to take control of your health and wellbeing?**
 - What do you do now to take control of your health and wellbeing?
 - What would help you to take control?
 - If you need help to take control of your health and wellbeing, who would you like to help you? How would you like to be helped? When?

Summary of findings

1. How can you be supported to live a healthier life?

What is stopping you from living a healthier life?

The main themes we heard from both events were around:



Access

- Cost - particularly due to transport, e.g. to appointments. Also, funding cuts to third sector / voluntary organisations who have previously provided help and support.
- Location - in Telford we heard that the need to use public transport can be a problem due to money but also the lack of support to help people go to appointments. In Shropshire we heard about the impact of rural isolation and the need to use more than one type of transport to travel to different appointments, e.g. bus, taxi
- Time - we heard that people believe that long waiting times/waiting lists are often due to a lack of staff. In Telford people commented on the length of time GPs spend with patients and appointments feeling rushed. More generally we heard that people feel they do not have the time to do everything they need to do, including taking care of their own health.
- Early intervention - people recognised a need for 'consistent and regular' intervention but felt that not enough people knew how or where to access this.

Isolation

- Social isolation and loneliness - these were identified as key factors as they can lead to not knowing what help and support is available and where it is. We heard that this can be more challenging if you do not have a named GP and a relationship with services.
- Homelessness - in Telford we heard about the additional difficulties experienced by homeless people and were told they are often 'turned away as they have no fixed abode'.

Information

- Communication - People talked about the impact of 'mixed messages' and not knowing what help and support is available, e.g. lack of advertising about 'available appointments'. In Shropshire we were told that 'organisations should be leading on what messages the public listen to, to be the trusted voice', and this information 'should be simple' and 'the channels of communication need to be appropriate for the person'. In Telford we heard that this information includes information about financial support.
- Education - Some people thought education could help from an 'early age', including giving people information about healthy 'lifestyles' and 'health promotion'. In Telford someone told us that they thought there should be more emphasis on 'teaching kindness, etc.' in schools as well as academic achievements.

What could help you to live a healthier life?

The main suggestions we heard were:

Services working together

- Model of care - In Shropshire people spoke about ‘moving away from the medical model to social model’ and that ‘specific information about issues/conditions [should be] given, not just treatment but community support’.
- Shared services / facilities - In Shropshire it was suggested that Community nurses could be on mobile libraries and it was hoped that ‘community hubs’ could be where services come together.
- Sharing information - including ‘service awareness (awareness of other options within the services themselves’. In Telford people explained the need for ‘GPs and other organisations [to] talk to each other and have a register for people who live on their own’ so that there can be a ‘telephone call to check up on people who live alone, say once a week. British Red Cross do’. The role of information technology was highlighted; ‘IT from different organisations need to talk to each other’.
- Best practice and research - For services to work well together a Shropshire resident suggested that ‘trusted networks’ (e.g. Parish Councils) share their experience and best practice of how to work well together. Another person said that Primary Care Networks should improve ‘sharing knowledge and experience amongst organisations’.



Building strong communities

- Improving access and ‘information about how to access help’ and services available. In Telford this was a role of ‘Care Navigators - [with] knowledge of what is important to you’. ‘Promoting what’s going on locally - getting together, walking groups, etc.’
- Raising awareness, e.g. of mental health and reassuring people generally ‘that it’s OK to seek help and not a failing’.
- Issues around food were raised in Telford, including the need for ‘better donations to food banks’, ‘reliable suppliers for home deliveries of food who check quality’ and ‘free home food deliveries for people who live alone’ (as you have to pay for delivery if it is under a certain amount).

What could health and social care services do to help you to live a healthier life? (Priorities)

Several priorities were identified. Providing:

Individualised care

- People felt it was important for people to feel that professionals are ‘treating ‘you’ as a person’ and for ‘professionals to take time for people - find out what they need and how to achieve this’

What would you do?

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Timely intervention

- The need to ‘target communities as well as the individuals (for prevention)’ and for ‘timely availability of services, rehab, support, etc.’ This was linked to a need for ‘investment’ in professionals and services so there is more of them and a ‘better spread of services around the county’. In Telford it was highlighted that services should be replaced if they are ‘lost’ (e.g. British Red Cross) and there should be ‘more recognition of third sector services by organisations’.

Investment in local people

- ‘Taking time to educate and understand people will help to relieve service strain further down the line’. For example, ‘encourage people to use other Health professionals - educate and raise awareness of alternative access points (e.g. pharmacy, nurses, etc.)’.
- It was suggested that there should be ‘early access - in life (e.g. teaching skills and raising awareness at young ages). Such as ‘emotional intelligence [which is] not taught in schools and should be’, supporting people ‘through adolescence and beyond’. Raising ‘awareness in school around physical/emotional health - involving families in education’.

2. What can services do to provide you with better care and support?

What is your experience of care and support now?

People at the events described a range of experiences (see [Appendix 5](#))

GP services were highlighted in both Shropshire and Telford & Wrekin, notably:

- Limited access to GP appointments
- Services available in GP practices - in Shropshire people commented on ‘traditional GP services being moved to hospitals, e.g. ear wax removal, phlebotomy’ and ‘Chiropody services cut from GP surgeries leads to impact on those with diabetes or sight loss’
- Mental health - in Telford we heard about the ‘battle between GPs and mental health services (depending on level and intensity)’

What small changes would make a difference?

People made a range of suggestions to tackle the issues, including:

Information sharing

- In Shropshire one person asked ‘Why is everyone so worried about data and confidentiality when information *needs* to be shared?’, ‘correctly work through what is confidential material and correctly share it’.
- It was suggested that for ‘complex care, there is one person to contact who takes responsibility rather than multiple contacts and this person needs to have good local knowledge, to be able to disseminate information to other professional/carers involved

What would you do?

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on key information like medication’. ‘Having a local point of advocacy (access) for signposting for extra support, continuing support and prevention’.

- Other solutions included:
 - ‘A shared care plan that works’
 - ‘Continuity of forms - for patients and professionals’
 - ‘Digital records so professionals can access patient information quickly’
 - ‘GP surgeries - better telephone system’

🔴 A range of communication methods

- We heard that people can get anxious waiting for an urgent appointment, ‘why not text, email or use the quickest form of communication rather than waiting for letters’, ‘don’t outsource appointment letter sending’

🟢 *In an ideal world, what would services do? (differently, more of)*

Suggestions include:

🔴 Joined up working within the NHS

- ‘Multi-disciplinary working - knowledge and skills sharing’, ‘physiotherapy attached to wards to enable patients to walk’,
- ‘Increasing rehab staff and Occupational Therapy provision’.
- ‘Specialists visits to GP services to work alongside GPs with complex cases to skill share’.
- ‘Joined up IT systems’

🔴 Joined up working with social care

- ‘Social services and NHS to work together - need to be one organisation’, ‘shared budgets’.
- ‘Regional/across an area planning’.

🔴 The role of housing

- ‘Better housing which works for people as they age’
- ‘Retirement villages where care levels can increase when needed’

3. What would make it easier for you to take control of your health and wellbeing?

🟢 *What do you do now to take control of your health and wellbeing?*

People told us about a range of things they are currently doing to support their own health and wellbeing, including:

- Mental and social activities - such as reading, socialising and being involved in groups (e.g. walking groups in the community), volunteering and ‘community involvement’, working towards a ‘Positive Mental Attitude (PMA) - Behaviour, attitude and meditating’ and ‘C.L.A.N.G (C - Connect, L - (keep) Learning, A - (Be) Active, N - (take) Notice, G - Give)’
- Physical activities - such as ‘walking’, ‘anything simple/intense’

What would you do?

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- Finding information for themselves - asking for signposting (including from GPs), finding ‘information in the community’, accessing ‘online guides, information and support’, ‘internet searches: symptom checkers’

Some of the barriers people identified to taking control of their health and wellbeing included:

- Lack of ‘motivation/resilience’
- Needing ‘quick and easy access to someone to get support and advice’ and finding ‘the right person to speak to’
- Access, for example the need for ‘24-hour access’ and ‘transport - bus routes, too far away, medical transport - need more’ (particularly if you have a disability or limited mobility)
- Fear and anxiety, including around travelling

What would help you to take control?

People made a number of suggestions, including:

- **Consistent, reliable information/guidance for all ages** - People told us there is ‘too much information - that can be contradictory, always changing’, and they would like ‘helpful guidelines (food/diet)’, ‘information given in an appropriate way (including signposting/social) by professionals’. One person felt it was important to keep ‘reminding, especially children, to connect with people physically rather than by mobile’
- **Support** - Including assistance for those people with ‘impairments’, people valued ‘peer support groups’ (e.g. Care and share groups for people with dementia)
- **Flexibility** - Such as a ‘flexible approach to working, e.g. shifts’
- *If you need help to take control of your health and wellbeing, who would you like to help you? How would you like to be helped? When?*

People told us that they wanted the help they are given to:

- ✓ Be ‘person-centred’ and ‘inclusive’, that ‘reduces stigma/labelling (shouldn’t be the only way you can get care)’
- ✓ ‘Recognise carer’s involvement. Value people’
- ✓ Be available through ‘one point of access with knowledge, support, who do I see?’, a ‘single point of access for information, advice and guidance’ that is provided by a ‘skilled/trained person 24:7’
- ✓ Take into account the fact people want to receive information in different ways (‘not everyone can use technology’) and from different people (‘prefer to have help from elsewhere, rather than a GP’)
- ✓ Be available early in order to prevent further needs, including ‘more social care input’
- ✓ Be ‘fast/rapid and the right treatment’

Meeting the health needs of people with dementia

Overview

In the seventy years since the founding of the NHS, life expectancy has increased by around 13 years; however, people are more likely to live with multiple long-term conditions, or live into old age with frailty or dementia.

One in six people over the age of 80 has dementia and 70% of people in care homes have dementia or severe memory problems. There will be **over one million people with dementia in the UK by 2025**, and there are over 40,000 people in the UK under 65 living with dementia today.

Dementia is of particular concern in Shropshire due to its large and growing ageing population:

‘Figures collected by GPs show that in Shropshire and Telford & Wrekin there are 4,751 people over 65 who have been diagnosed with some form of dementia.

But, estimates from the NHS, based on the on the age profile and gender of patients, suggest the real figure for the county could be as high as 6,831.

That means an estimated 2,080 pensioners are living with the debilitating illness that has not been formally recorded by their doctor.’ (Shropshire Star 22/12/18)

‘As far as Shropshire health conditions go, we believe that dementia is a “sleeping giant”... one that has begun to wake up.’ ‘Projections show that by 2031, 45% of the South Shropshire population will be over 65 years of age and will be among the three oldest populations across England and Wales.’ (Shropshire Dementia Strategy 2017-2020, Shropshire Clinical Commissioning Group / Shropshire Council)

Over the past decade the NHS has successfully **doubled the dementia diagnosis rate and halved the prescription of antipsychotic drugs**. It has continued to improve public awareness and professional understanding.

Our findings

Long Term Condition Questionnaire Respondents

In the questionnaire about NHS support for specific conditions nine people, four from Shropshire and five from Telford & Wrekin, told us about their experiences of dementia support.

Healthwatch Shropshire and Healthwatch Telford & Wrekin also attended a number of focus groups, speaking to people with dementia and their carers:

Healthwatch	Number of groups	Number of people with dementia	Number of carers
Shropshire	10	35	40
Telford & Wrekin	6	13	9

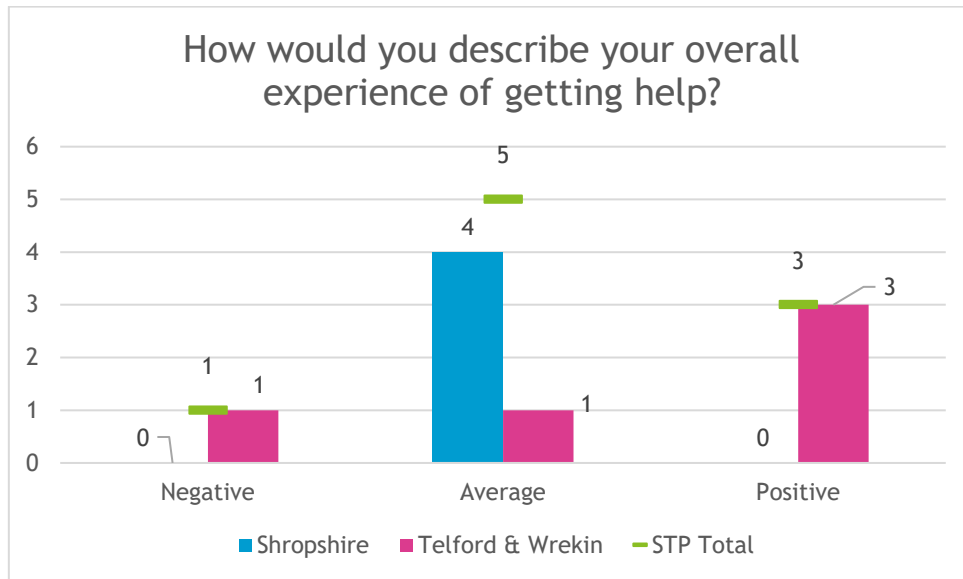
For full details of the focus groups and findings, see [Appendix 3](#)

Overall Experiences

Questionnaire Responses

Nine people living with dementia responded to these questions:

Getting Help



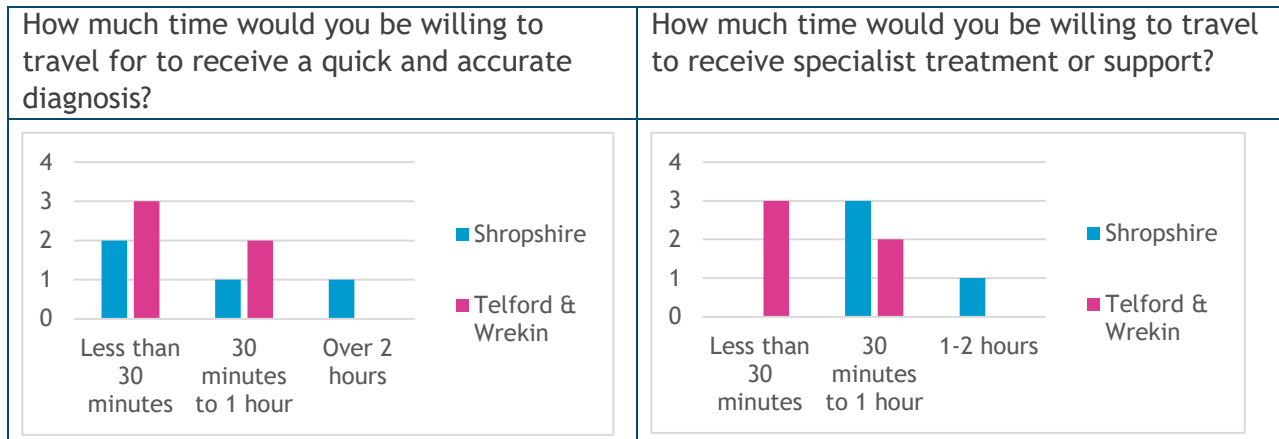
All four respondents from Shropshire felt their experience was ‘average’ while the majority of Telford & Wrekin respondents described it as ‘positive’. The responses do not give us the information needed to identify why their experiences might be different, e.g. if it is due to a variation in expectations or due to the fact that Admiral Nurses work in Telford & Wrekin but not in Shropshire.

Communications

When asked if people received timely and consistent communication three of the nine respondents felt they did, four they did ‘somewhat’ and two that they did not.

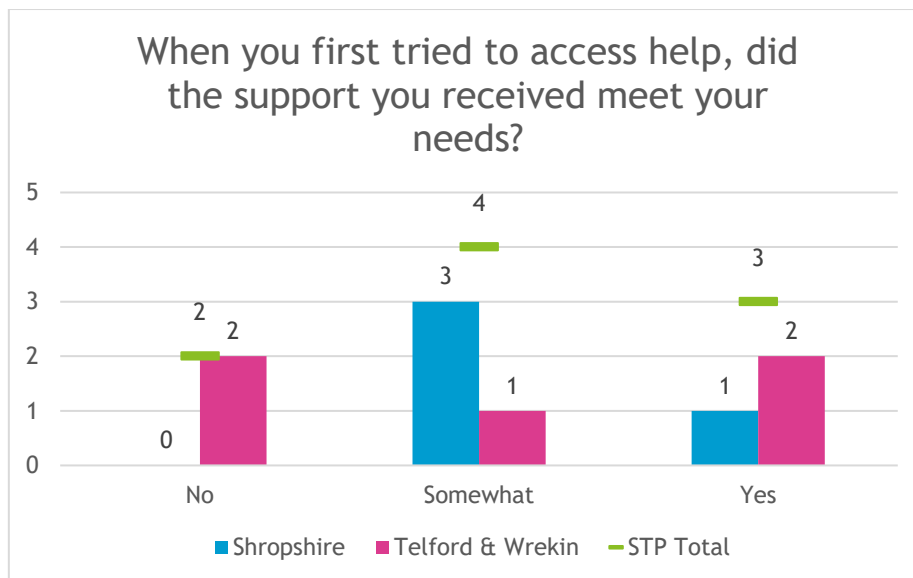
Transport and Travel

All respondents' main means of transport was their own or somebody else's car.

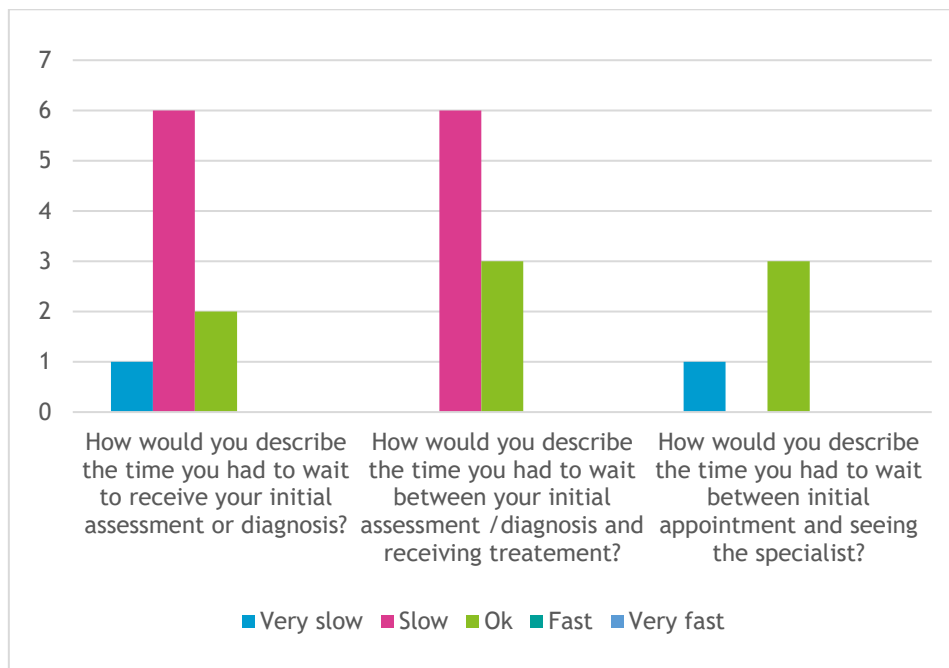


Assessment, diagnosis and treatment

Questionnaire responses



How would you describe the time you had to wait?



Focus group findings

The people who attended the focus groups were asked:

- What was it like when you (your family member) received a diagnosis of dementia?
- What support would you have found helpful at this time?
- What could have made that experience better?

Please note: Some comments from the focus groups are followed by a group code as shown in the [appendix](#) to indicate if the comments relates to Shropshire (S) or Telford & Wrekin (T). No differentiation is given to comments from carers or people living with dementia.

Receiving a diagnosis

A number of people we spoke to could not remember being given a diagnosis, those that did told us the experience was emotionally hard and overwhelming:

- “felt like crying but I had to keep saying to myself pull yourself together” S7
- “The process was unbelievably horrendous; I was just told I had it and that was that” S9
- “Overall, the diagnosis was traumatic for family members and the patient themselves” T1
- “Like getting hit in the face with a baseball bat...I’ve had dementia for a while I can’t tell you how long” S9

One person living with dementia said that

- “Dementia isn’t just a ‘memory problem’. Its brain failure. It should be classed on the same level with heart failure and liver failure. That would help make it feel like it’s not your fault”

Support around diagnosis

People told us about the time they had had to wait to get a diagnosis. For example, of the five people attending a support group in Shrewsbury, four told us it had taken over two years with a second scan being given.

Carers told us they were not always heard when noticing early changes and sharing concerns and this led to frustration and a delay in getting a diagnosis. Wives were reported as being the first people to really notice the differences in behaviour and although each one was aware of changes within themselves. Several were initially told it was nothing and don’t worry about it, with one GP saying he had similar problems. Family members commented that the most difficult part of diagnosis was the feeling they were not listened to.

- “It would be good if GP’s were less dismissive when the family highlights that a problem is developing”

The most commonly reported pathway to receiving a formal diagnosis was: GP appointment, GP refers to the Memory Service who diagnose by using simple tests and one or two scans. In one group it was commented that the tests done by the Memory Clinic during diagnosis don’t feel like they reflect the seriousness of the diagnosis.

Improving the experience of diagnosis

- Mis-diagnosis

We heard accounts from people who had been initially misdiagnosed or told it was “nothing” and not to worry about it, particularly amongst the young-onset group. One person told us that had gone to their GP for a whole year, each time answering the same set of questions. Another had initially been given antidepressants. Four member of one group told us they had first been told by the Memory Clinic that they had depression and stress and one of these was told he had obsessive-compulsive disorder.

- “Diagnosis part being extremely hard due to [husband] having a very high IQ, doctors mistakenly saw this as an advantage and disbelieved our concerns. Once eventually diagnosed there was not a lot of support given from the Memory Clinic either” T1

- *Timely information and guidance*

People said that getting the right information at the point of diagnosis would have helped “so that you don’t feel alone and can get help if you need it” (including around finances). Some people said that information should be staggered rather than given all at once. People said that

some information was not appropriate at that particular time; although it was useful it was put away and not read. Suggestions included:

- After having an “assessment with the memory clinic [] at that point it would have been helpful to have a flow chart to point her to information and groups for support. This could have included information about which benefits to claim for etc.” S8
- “You could be given information on what to search and where to find it, so you can go at your own pace”.S7
- “I think hospitals and GP practices ought to have pamphlets regarding support groups” S9

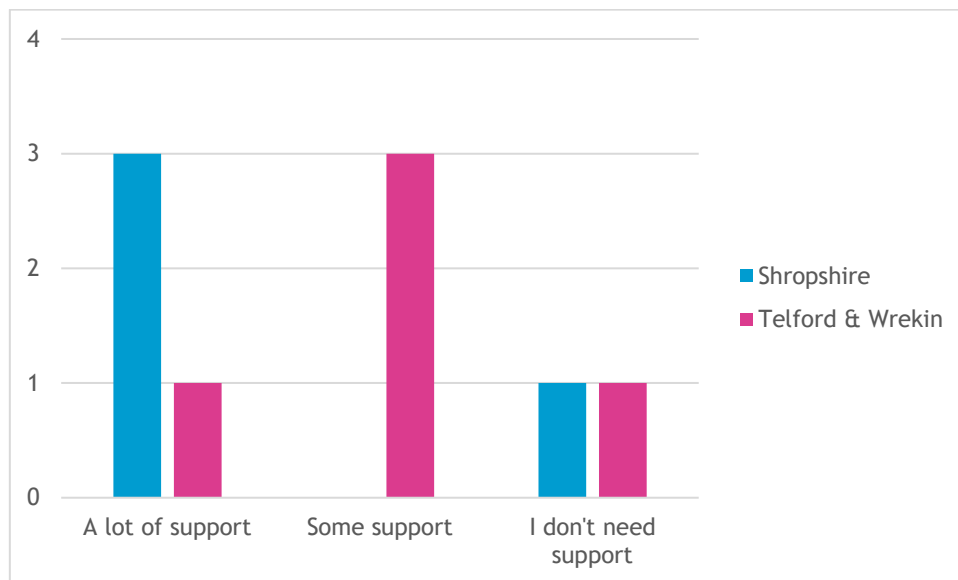
People also wanted some guidance, including on which information / support groups are “best”:

- “One point of contact would have been helpful, someone to reach out too instead of multiple amounts of information” T3
- “Hardest part was the uncertainty of what vascular dementia was time line etc. There was not a lot of information given verbally just many leaflets to read through which was overwhelming” T4.

The provision of ongoing care and support

- What level of support do you want the NHS to provide to help you stay healthy?

Questionnaire responses



After diagnosis one person found it ‘Easy’ or ‘Very easy’ to access on-going support, four found it ‘Difficult’ or ‘Very Difficult’ and four said it was ‘OK’.

When asked if the support options offered met expectations, three people replied that it did, two replied somewhat and two replied that it did not.

Focus group findings:

Care Plans

During focus groups we asked people:

- How useful is your care plan?
- Have you been involved in developing/writing it?
- What would you like to see in a care plan?

Most people had no or little knowledge of care plans and many were not aware of the GP or Memory Service having a care plan. Only a small number of the group were aware of a care plan being in place, or had seen a care plan. In one group, only one of the five people living with dementia had seen their care plan. One person told us:

- “If you need us, phone us. That was my care plan” T5

Many people commented that this might have been something that had been set up at first diagnosis but if that was the case it had not been reviewed or mentioned since.

Those that were aware of Care Plans told us that the content and usage were inadequate:

- “Who looks at that?” “As the staff come into D’s home they are basically unmonitored and it is up to the individual whether or not they read it. When the supervisor visits, she will not know if things are in order because I have been in and sorted things out or not.” S8
- “Very little meaningful within them”
- “A care plan is a care plan - it doesn’t tell me what will happen to me and it doesn’t tell me what to do”

Support post-diagnosis

We asked the focus groups:

- What support have you had since your diagnosis?
- What support do you/ would you find helpful?
- Where would you like to receive this support, e.g. at home, in a local setting?

We heard that:

- “The post-diagnosis time is the most frightening. You really should have immediate support at this time to help with the shock”

Continuing, timely information remained a key theme and some gaps were identified.

People told us about the information that had been given following their diagnosis, e.g.

- “Post-diagnosis, we received a book of information that talked about the next steps and what dementia meant” S1

The type of information given varied and was not easily available to all and did not always take into account people's needs:

- “My GP practice are hoping to create and give us a leaflet that explains what dementia means to the person”
- “I was told to get info from so-and-so, read a book... I CAN'T read as I forget what I've been reading, it's useless.”

One person told us that she had found a coping course about dementia online that was free and it had helped her greatly however this has been cut due to funding. She said, “That could help so many people”.

Other people wanted specific information and support about:

- incontinence
- wills and probate
- mental capacity and Power of Attorney
- driving and the DVLA
- using public transport

GPs and Primary Care

In focus groups there was a great deal of discussion centred on GP surgeries including appointments and the level of support from the GP themselves.

Some people felt they had been well supported by their GP:

- “I have full confidence that if needed I could get a GP phone about to talk about my concerns, outside of our 6 monthly check up”. (Bridgnorth Medical Practice)

While others did not:

- “The GP never asks me how I am coping.”
- “For me support from this group but not much from the GP.”
- “They [GPs] don't believe people that young have got it”

There were concerns around the difficulties in getting appointments and being able to see the same GP. We heard that some GPs tell patients to follow up with them directly, but when the patient tries to do so they are told they have to speak to whoever is available.

- “You have to fight to get the GPs out to you.”
- “Getting a GP appointment is very hard.”

Some people felt GPs should work more closely with other services:

- “Closer communication between the GP and the Memory Service regards medication would be helpful”
- “GPs should consider dementia as a potential diagnosis with younger patients. There is a guide for GPs from Young Dementia UK which is very helpful and is on line.”

Memory service

The Memory Service received mixed reviews about how helpful the intervention and support had been. The Psychiatrist had visited one couple who found that extremely helpful. They were able to go through medication in detail and were told they would have another appointment within 3 to 4 months.

Other positive comments include:

- “The memory service is our sanity.”
- “The Bridgnorth Memory team are very respectful, took the time to explain to both my husband and me as his carer. My husband was given 12 weeks of 30 min counselling sessions so that he could talk about how he was feeling.”
- “I phoned the memory service and within two hours the problem was sorted”

While other people told us of less positive experiences and the difficulties accessing the support needed. One person told us that the memory clinic called every 6 months for a ‘chat’. If the carer said that all was ‘ok’ then it was decided an appointment wasn’t necessary. Another person said they had had such a bad experience when being told of their diagnosis that they refused to have anyone from the clinic in the house.

Other comments were:

- “Memory care service very helpful but it would be helpful if it was the same person each time as having to keep explaining yourself and the situation is difficult.”
- “Not a great service, lost touch with them”
- “No follow up to see how we are, which groups have helped us etc.”
- “The Memory Clinic are good for technical understanding, but you don’t feel that they have proper practical understanding and knowledge of how hard dementia can be and what it means. We need more practical help.” S1

Support/social groups and courses

People told us that groups are valued especially long standing ones and they are concerned that a lot of groups are stopping when there is a need for more offering a range of activities for people with a dementia diagnosis:

- “You go to other things, as soon as you say ‘dementia’ they look at you like you’re totally thick”
- “I love gardening, but no gardening groups available. Me and my wife would love to still be able to enjoy these things together”

One person with dementia particularly emphasised the need for groups that she and her husband could go to together. She is worried about speaking to people without him there. She wants to socialize but needs his support.

We heard that the Memory Group at Bridgnorth is so valued that when faced with closure or paying £5 each all members present agreed to continue and pay.

What would you do?

45

At one group in Shrewsbury we were told:

- “The Midlands Partnership Foundation Trust Memory Service is closing two support groups and two carers support groups this summer. The reason given was that there was an imbalance in the provision for the young onset compared to the older group. Now that the two are merging what is the reason? Given that there are over 4800 people in Shropshire with dementia there is only sporadic support available.”

Feedback about the importance of support groups included:

- “Mayfair centre - very helpful especially letting everyone know what is happening. E.g. this Care & Share Group, Breathe Easy all have to be self-funded.”
- “She attends ‘Connect for Life’ on Wednesday every week 10.30 - 2.30 where she has a cooked lunch and she is very happy with this. They have different people to talk, sing, games, they are friendly, helpful and comfortable.”
- “I like coming to here (dementia football he is driven by group leader) it’s very friendly”
- “The ‘Singing for the Brain’ group is what keeps us going.”
- “Having support after my diagnosis has been very important, we enjoy ‘Singing for the Brain’ and the Age UK groups. They are very important to us all as a family”
- “Having to find your own support stream is frustrating but nothing would stop me I’m still an active gentleman, I need stimulation not leaflets and sent away!”

Many of the groups offer courses and practical information which people find invaluable:

- “The courses ran by Alzheimer’s Society for Carers are very helpful. Gives you information on how to look after yourself as a Carer as well as information on dementia. One session a week for 4 weeks”

Hospital

The people we spoke to shared a range of experiences of being in hospital:

- “She had a fall and was very ill in hospital which she doesn’t really remember.” J reports “the ward sister was extremely helpful. Rails and adaptations were put into the house at this point by the Occupational Therapy Department”.
- “Oswestry (RJAH) are very good [...] way ahead of the NHS [...] they are aware of everything. My wife told them I have dementia and it’s all in my notes. She could stay with me until I was put under” T5

We heard about the use of ‘This is me’⁸ and the Butterfly⁹ symbol to indicate a dementia diagnosis but people felt they were not used well by all staff and departments:

⁸ ‘This is me’ is a simple leaflet for anyone receiving professional care who is living with dementia or experiencing delirium or other communication difficulties’ www.alzheimers.org.uk

⁹ ‘The Butterfly Scheme provides a system of hospital care for people living with dementia or who simply find that their memory isn’t as reliable as it used to be’ <https://butterflyscheme.org.uk/>

- One person had been in hospital in Birmingham and their ‘This is me’ form was put in a drawer and not referred to. There was a butterfly at the back of his bed, however he was repeatedly asked, by his Consultant, ‘how do you feel compared to yesterday?’ His reply was always ‘I don’t know I don’t remember yesterday’.
- A couple said that, while they were happy with the operation at RJAH, they were distressed by the lack of awareness of dementia despite completing a form about his history at an outpatient appointment. Throughout his stay on the ward his wife had to repeatedly explain his condition which they found “embarrassing”.
- Another person told us that the Butterfly symbol worked very well whilst in hospital for a knee replacement operation in Robert Jones and Agnes Hunt Hospital (RJAH). However this did not link through to booking appointments and the outpatient appointment itself.

One person told us:

- “They put a butterfly above the bed [in the hospital] but that was it.”

Support for families/ carers

We spoke to 49 carers across the focus groups and asked

- As a family member what support have you received?
- What support would you like to help you stay well?
- What information has been made available to you and has it been useful?

We heard that there is a massive need for ongoing information, practical help and support and respite for carers.

- “Carers and patients need practical support, not policy.”
- “Someone you can ring in a crisis for help and advice, not just through the week, but out of hours and weekends”

Carers told us that a lot of what they know they are learning from groups and the experiences of others. One person told us:

- “It would be nice to have someone come and tell you that you are doing the right things”

People welcomed the support provided by Admiral Nurses, not just to the person with dementia but the family unit.

- “Admiral nurse has been wonderful.”

However, other people felt that not everyone receives the same level of support:

- “I feel like people who live in other areas are getting different levels of support [sometimes better]”
- “Should be more support, no one prepares you for the reality you will leave with a long term bereavement. More should be offered, what would happen to her if something happened to me?”

People told us that carers needed someone to come and help who could:

- “Help with tasks like cleaning in the home, chat with person with dementia and carer, and stay whilst the carer goes out for short period.”

Particularly if there are no friends or family nearby.

People told us that ongoing, regular respite is needed:

- “Respite care is very important - particularly like a local care home where someone could be dropped off in the morning and then collected after lunch.”
- “The only respite we’ve been offered is some a few days to a week, as a one off. But what we need is ongoing support for a few hours a week”

At one focus group we heard that consistent support to give carers free time for themselves would be the biggest help. They also agreed that being offered support, rather than having to ask all the time, would be helpful.

- “Planning who to ask for help can feel like a marathon sometimes”

Common themes from the questionnaire

The responses to questions in the questionnaire around the quality of support that respondents had experienced, what they felt could be improved and what they felt the NHS could provide showed some common themes. These themes have been collated to indicate the areas of support that respondents commented on most. A full count of the themes is in [Appendix 2](#) along with the question answers on which they are based (questions 6b, 13, 14, 18b, 19b, 25, 26).

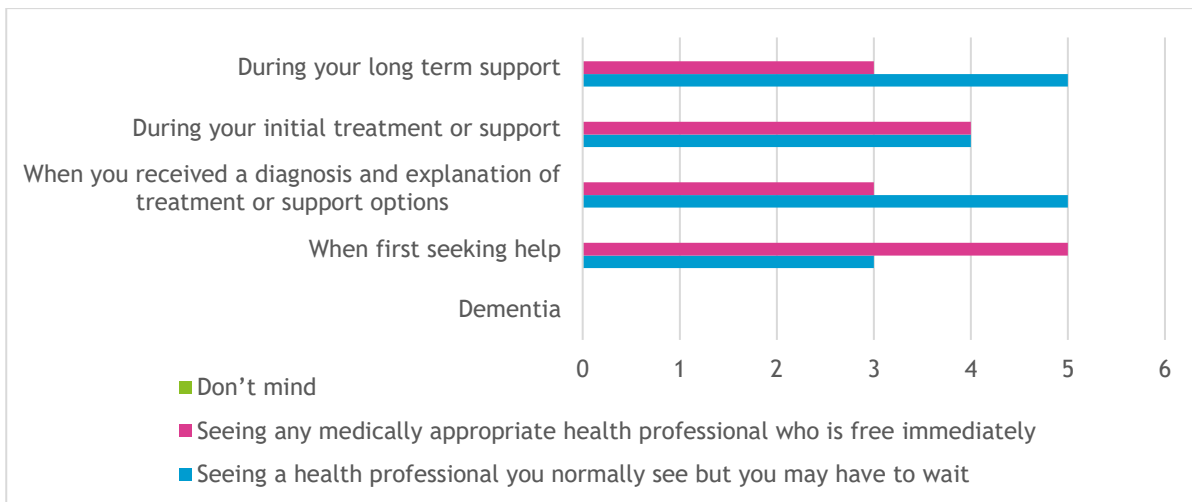
The two main themes from the questionnaires were:

1. **Support for carers** - Two respondents identified the lack of resources to meet the needs of carers as an issue
2. **Information and advice** - Two respondents called for more information and advice; “my son got a diagnosis and that was it, I have no idea what to expect or what help we can get”, “more specialist advice

Multiple Conditions

Five people who completed the questionnaire had additional conditions and two of those felt that it made getting support harder, two thought it made no difference and it was not applicable to one.

What is most important to you at each stage of your care?



Prevention and/or early intervention

Questionnaire responses

When asked about the time people had to wait for their initial assessment or diagnosis two people described it as ‘Ok’ and seven as ‘slow’ or ‘very slow’.

Focus group findings:

At a focus group we were told that work should be done to raise awareness of dementia so that people feel better prepared. This is life changing for the patient, their families and carers:

- “All it takes is one person, one pathway to have guided me on where to go and which support we would need. One point of contact would have helped us all”

Preventing hospital stays:

At a focus group in Ludlow, one carer had recently experienced the Integrated Community Services (ICS) Team (made up of staff from the Community Health Trust and Shropshire Council). This worked extremely well after her husband had fallen and had a urinary tract infection. A social worker visited and put in a package of care for two weeks, which included getting walking aids and carers. More help was offered that the carer decided to accept. They accepted morning and evening daily visits. It was “wonderful” to have the package provided rather than her trying to piece it together and seek out all the services they needed herself. This helped reduce her stress and she was pleased that a hospital stay was avoided. This was exactly what she needed.

Links with other related work

● 'Dementia in Shropshire and Telford & Wrekin'

Our findings here reflect those issues highlighted by a survey completed by the Dementia Action Alliance in Autumn 2018. The most frequently mentioned areas were:

- General Practice
- Hospital care
- The needs of unpaid care givers
- Social inclusion and activities

The DAA found that:

'Regarding General Practice, issues included difficulties making appointments, lack of continuity of care, lack of regular reviews, and staff not understanding dementia'.

'Unpaid care givers told us they do not receive the support they need to remain strong and healthy, and to have the chance to live their own lives'.

'Respondents strongly voiced the need to maintain social engagement through activities and groups that are dementia friendly and inclusive'.

This study also highlights the essential nature of peer support and the benefits that are gained through social activity.

Hospital admissions and outpatient appointments were also raised within this report and the lack of staff understanding of how to care for someone who is living with dementia.

- **Healthwatch Shropshire Enter & View Reports to Care Homes registered by the CQC as providing dementia care**
- **Healthwatch Shropshire Enter & View Summary Report 'The NHS Accessible Information Standard in GP Practices' (2018)**

All published on [Healthwatch Shropshire website](#).

These reports support what the DAA survey says, and what we have heard, about the importance of a safe and 'Dementia Friendly' environments for people living with dementia and their carers. One of the DAA conclusions is that 'Shrewsbury and Telford Hospitals NHS Trust should adopt and implement the Dementia Friendly Hospitals Charter' and that GP surgeries should work with the DAA to become Dementia Friendly. The Healthwatch Shropshire report into the NHS Accessible Information Standard in GP Practices also recommends that those people working to support people with dementia and their carers are trained in the requirements of the standard and information is available in a range of formats to make sure it is easy to read and understand.

Summary

Our findings show that what matters most to people in Shropshire, Telford & Wrekin who are living with dementia and their carers is:

1. Receiving timely, on-going, reliable information, including:

- Information about the diagnosis and on-going support available, e.g. for incontinence
- Information about local support / social groups (either dementia friendly or specifically for those with dementia and their carers), help and advice about using public transport
- Practical information, e.g. wills and probate, mental capacity and Power of Attorney, driving and the DVLA

2. Support for carers, including:

- Weekly, planned breaks from caring responsibilities while their loved one is cared for in a safe environment, e.g. Day centre, 1:1 care at home
- Having their concerns heard and responded to, e.g. around diagnosis, the need for help
- Support for their own emotional health and wellbeing, e.g. emotional support and reassurance that what they are doing is the best for their loved one

3. Access to and on-going support for the person with dementia and their carer, including:

- Seeing the same GP
- Priority GP appointments, longer appointments, in particular for emergencies
- Crisis support out of hours and at weekends
- Help to link in with other services and information about the support available, possibly from a named link worker
- A consistent approach to identifying, recording, flagging and sharing the needs of people with dementia and their carers to prevent repetition, in line with the NHS Accessible Information Standard
- Consistent Memory Service provision across the County
- Effective and consistent use of Care Plans, 'This is me' and the Butterfly symbol

Improving support for people with learning disabilities or autism

Overview

More than 1.2 million people in England have a learning disability and face significant health inequalities compared with the rest of the population. Autism is a lifelong condition and a part of daily life for around 600,000 people in England. It is estimated that 20-30% of people with a learning disability also have autism.

On average, adults with a learning disability die 16 years earlier than the general population - 13 years for men, 20 years for women. People with severe mental health illnesses tend to die 15-20 years earlier than those without.

In 2017, the Learning Disabilities Mortality Review Programme (LeDeR) found that 31% of deaths of people with a learning disability were due to respiratory conditions and 18% were due to diseases of the circulatory system.

Since 2015, the number of people in inpatient care has reduced by almost a fifth and around 635 people who had been in hospital for over five years were supported to move to the community. However, this has led to greater identification of individuals receiving inpatient care with a learning disability and/or autism diagnosis, so increasing the baseline against which reductions are tracked

The Long Term plan focuses on three main areas:

- Identification and recording;
- Health promotion and screening;
- Personalised support, including moving care closer to home.

Questionnaire Respondents

Learning Disabilities

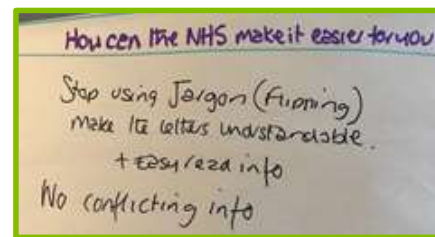
In the questionnaire about NHS support for specific conditions 19 people, ten from Shropshire and nine from Telford & Wrekin, told us about their experiences of support for learning disabilities.

Autism

In the questionnaire about NHS support for specific conditions 11 people, three from Shropshire and eight from Telford & Wrekin, told us about their experiences of support for autism.

Focus Groups

Taking Part, the Independent Service for people with Health and Social Care needs in Shropshire and Telford & Wrekin, facilitated focus groups across both areas. They spoke to 58 people, 48 in focus groups and ten in one to one sessions. Of the 48 people in the groups, there were 42 people with learning disabilities, four with autism and two with both. Eighteen people reported having other long-term conditions.

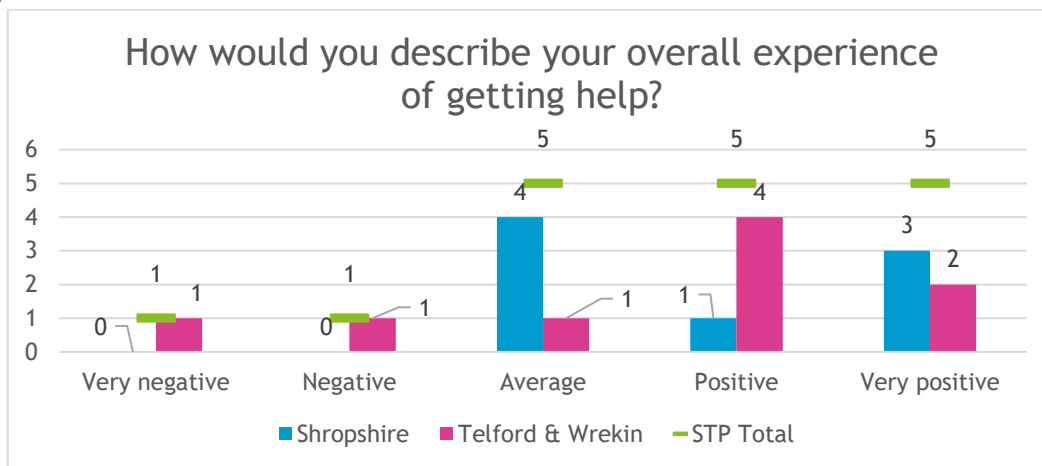


Overall Experiences

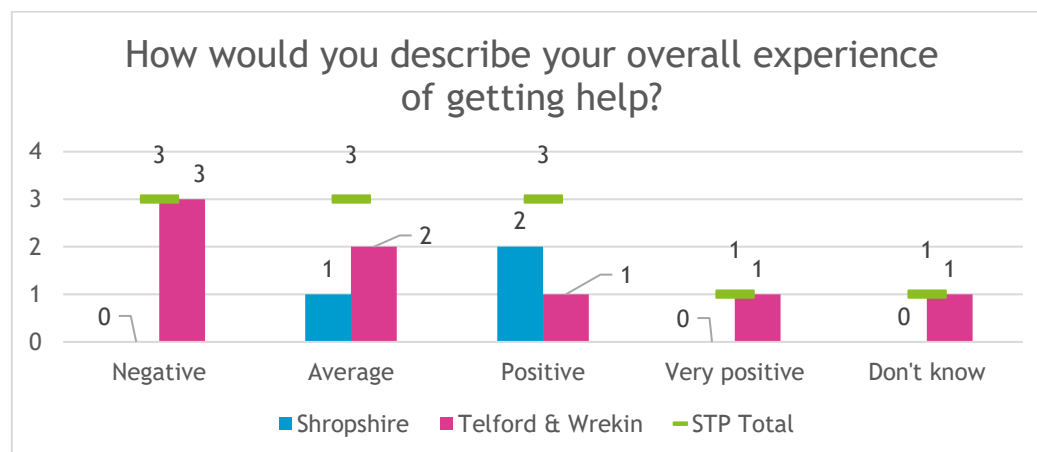
Getting Help

Questionnaire respondents

Learning Disabilities



Autism



Communication

Learning Disabilities

When asked if people received timely and consistent communication seven of 17 respondents felt they did, five they did ‘somewhat’ and five that they did not.

The Expert by Experience focus group outlined the need for clear communication:

- Don’t assume I understand because I say I do, reflect /check.
- Better training for health workers.
- Use easy read information, letters and leaflets.
 - “Both times they spoke to my Mum more rather than me”
 - “Problems understanding him because of his accent, but he repeated himself”
 - “Understand that we can’t always read/understand side effects” [of medical treatment]
 - “Easy read information is so important”
 - “No conflicting information”
 - “Stop using jargon”
 - “Health people need training...train more doctors on awareness” [of disabilities]
 - “Reception at hospital needs to be better- needs better training”
 - “Train medical people about MCA. They don’t understand it properly”

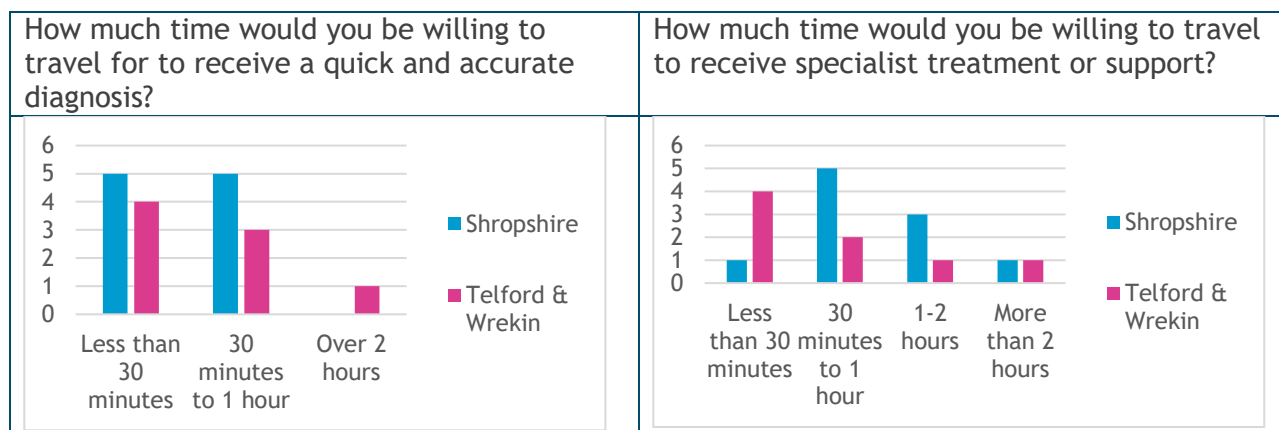
Autism

When asked if people received timely and consistent communication four people felt they did, four they did ‘somewhat’ and one that they did not.

Transport and Travel

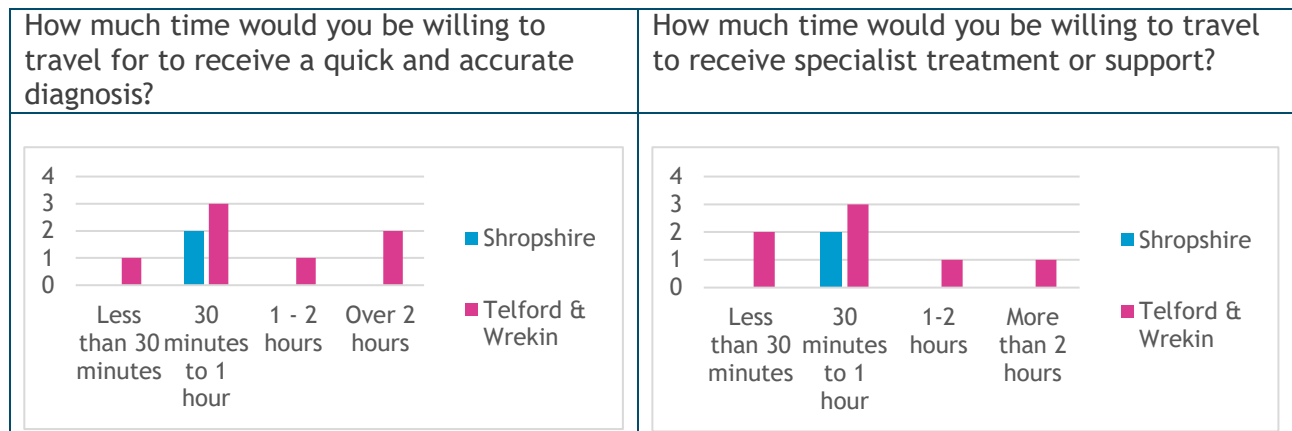
Learning Disabilities

All respondents main means of transport was their own or somebody else’s car.



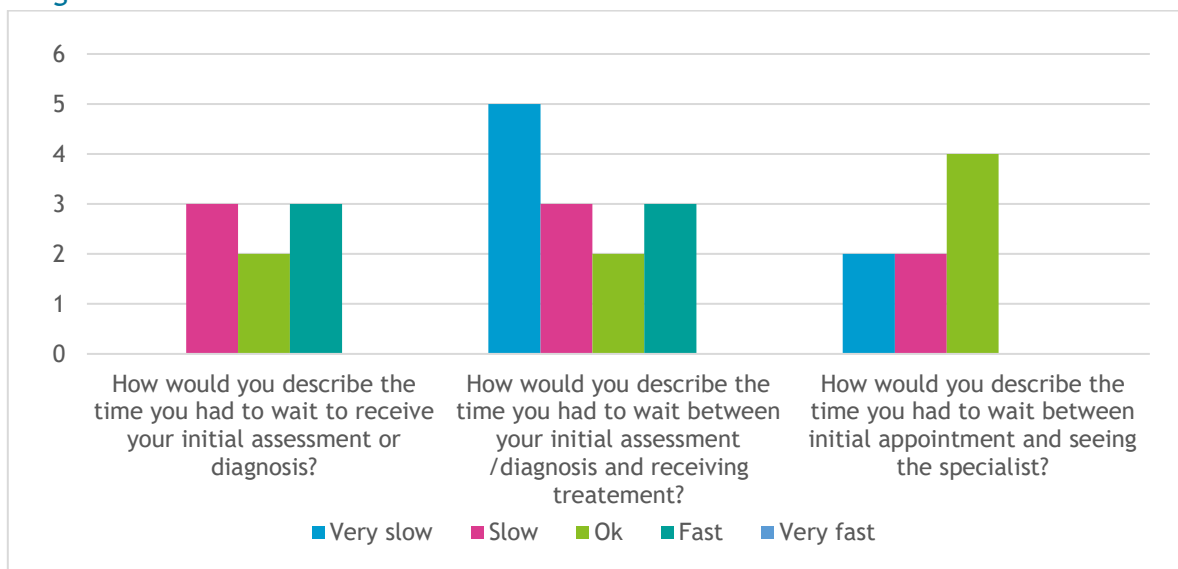
Autism

Most respondents main means of transport was their own or somebody else’s car, one person used a taxi.

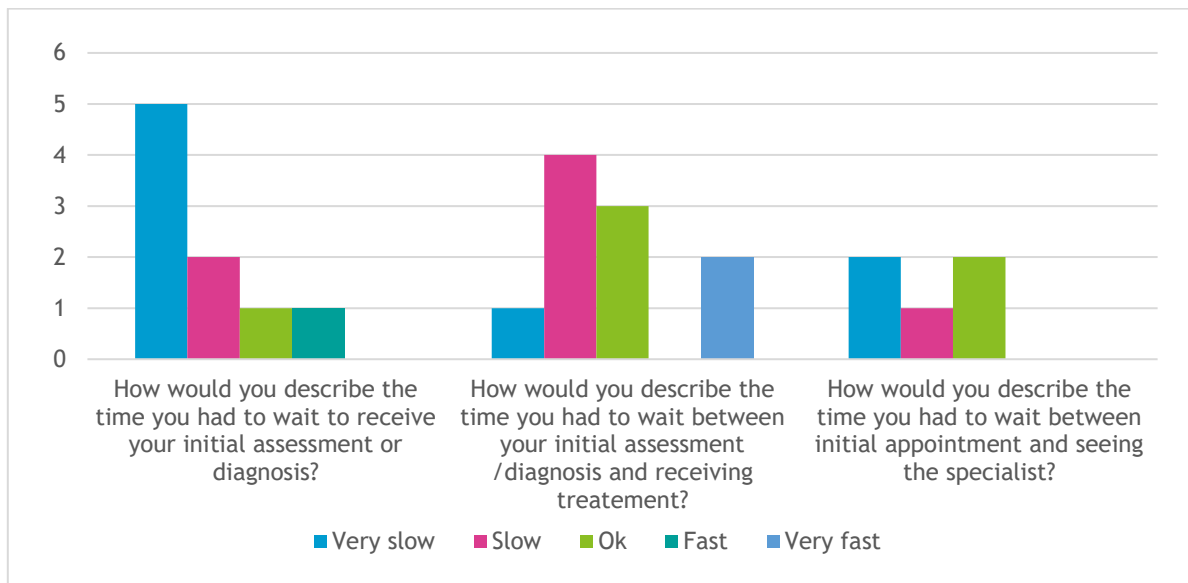


How would you describe the time you had to wait?

Learning Disabilities



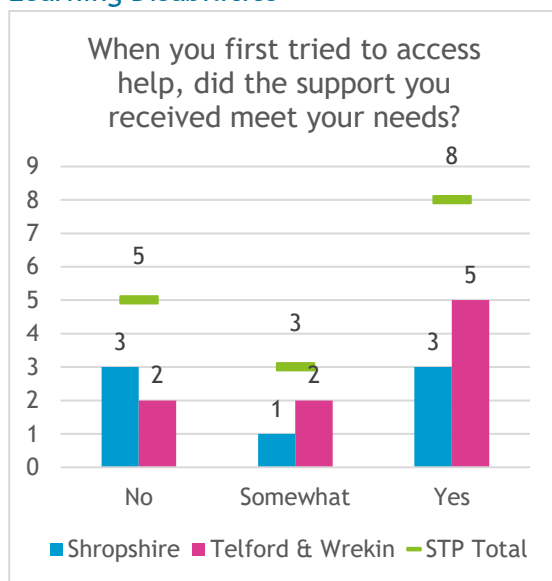
Autism



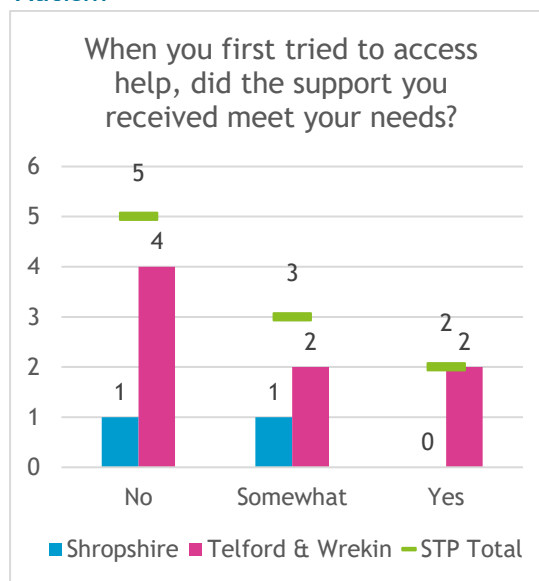
Assessment, diagnosis and treatment

Questionnaire respondents

Learning Disabilities



Autism



Focus group findings

As well as the need for clear communication the Expert by Experience focus groups outlined these key elements:

- **Consistency, access to the same doctor** is vital. Know me well; know me when I feel well, know what’s normal for me. Parity across the county with Annual Health Checks.

What would you do?

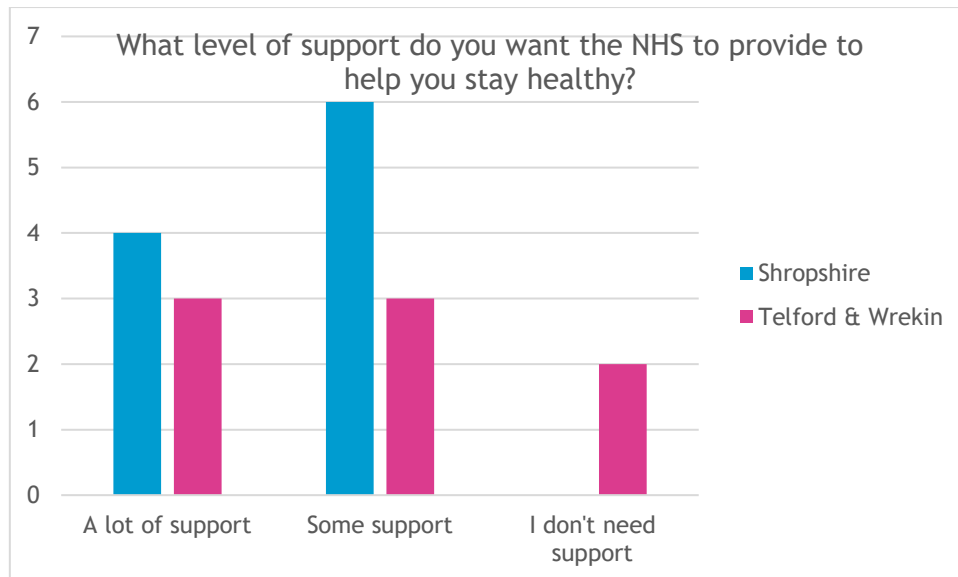
- “I have had to wait 1 ½ hrs (waiting time) for my doctor, but they are good if I can have my own doctor.”
 - “I don’t get to see my same GP every time, and that’s not good.”
- **Compassion**, understand that I am a person not a ‘condition’ and do not let my disability overshadow other potential conditions.
 - “Sometimes the receptionists ask too much [personal info]
 - “They [medical staff] do things automatically; we need things done step by step, makes it less scary.”
 - “If you don’t understand our conditions, please research it first”
 - “Don’t think [assume] we all can use computers”
 - “We’d need a lot of support with this” [accessing/managing care planning and online appointments etc.]
 - “Keep us informed”
 - “Come to us” [come into their world Day Services etc. when talking about prevention work check-ups/training/awareness work etc.]

The provision of ongoing care and support

Questionnaire responses

- What level of support do you want the NHS to provide to help you stay healthy?

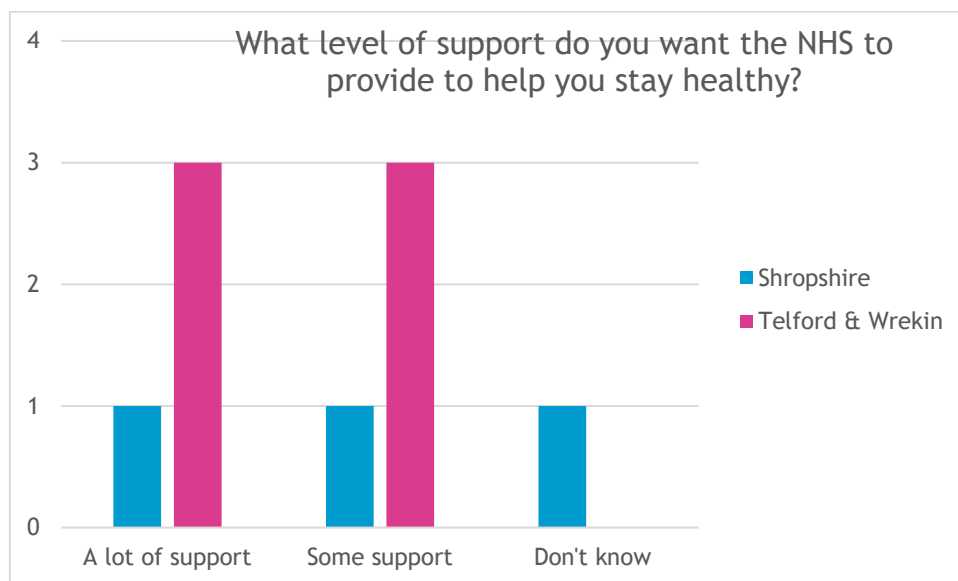
Learning Disabilities



After diagnosis three people found it Easy or Very easy to access on-going support, three found it Difficult or Very Difficult and five said it was OK.

When asked if the support options offered met expectations, eight people replied that it did, two replied ‘somewhat’ and four replied that it did not.

Autism



After diagnosis one person found it Easy or Very easy to access on-going support, two found it Difficult or Very Difficult and four said it was OK.

When asked if the support options offered met expectations, three people replied that it did, two replied ‘somewhat’ and four replied that it did not.

Common themes

The responses to questions around the quality of support that respondents had experienced, what they felt could be improved and what they felt the NHS could provide showed some common themes. These themes have been collated to indicate the areas of support that respondents commented on most. A full count of the themes is in [Appendix 2](#) along with the question answers on which they are based (questions 6b, 13, 14, 18b, 19b, 25, 26).

Learning Disabilities

Themes identified included:

- **Communication with the patient** - Four people identified this as important, e.g. “Good thorough H Check at the doctors, [they] are good, they sign, I can understand / they take time”, “Keep checking up on me. Make sure I am ok”
- **Information and advice** - Four people mentioned this, e.g. “My son got a diagnosis and that was it I have no idea what to expect or what help we can get”, “More specialist advice”

Autism

Themes identified included:

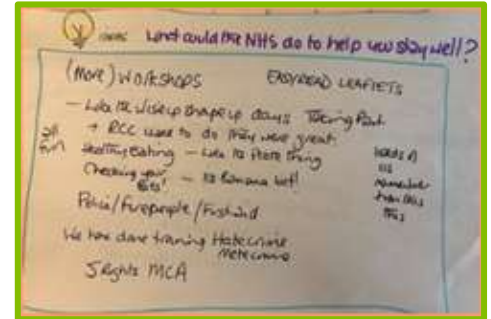
- **Information and advice** - four people told us how important this is, e.g. “We spoke to our health visitor about it and she gave us lots of information and places to reach out too”, “Learning help about dangers, road safety. Maybe workshops for carers/parents. Expert help on foods with sensory issues.”

- **Access to specialist service** - three people highlighted this importance of speak to the right person at the right time, e.g. “Felt like I was passed around from person to person”, “I had many appointments before being given support. I saw so many different people”

Focus group findings

Appointments

The focus groups highlighted the difficulty in making appointments with doctors, having to call at a certain time and not being able to get through to the surgery. Only a few people are able to deal with this, with carers going to the doctors to book appointment in person.



- “Making appointments is difficult, you have to ring, say at 8 o’clock and you can’t get through, it’s hard to get an emergency appointment”
- “Not easy to get an appointment, the set time to ring is stupid, you can’t get through, it needs to be sorted”
- “My carer goes down [to the surgery] it’s the only way [to book an appointment in the end]”

Carers

The importance of carers was apparent from the focus groups feedback. Vital for people to be able to access health services, most people need ongoing support from a person that they trust for practical reasons, i.e. travel, following directions, reading letters etc. Also for emotional support and help with understanding processes and choice making.

- “Even now I am constantly misunderstood by [medical staff]” [This comment, when talking about why having someone like a carer with you is vital, someone who the person can trust and knows well]
- “After my experience [of the doctors] I felt I had to take someone with me the next time”
- “It’s hard to go to my doctors on my own” [Even independent people said they wouldn’t go alone]
- “We need to get supported to go to things like doctors”
- “It’s most important for us to have carers with us, someone we can trust; talk to my carer so they can help to explain to me, but talk/explain to me too.”

Most people spoken to in the focus groups ‘do not differentiate health care services, the NHS including primary care is one thing, you are ill/had an accident you need help to get better, who the people work for (that are helping you) are not so important or relevant.’

	Do you get good support from your doctors?			Do you get good support when you go into hospital?			Do you get good support when you see a specialist?		
	✓	–	✗	✓	–	✗	✓	–	✗
Shropshire	9	8	3	5	2	1	2	2	1
Telford and Wrekin	14	1	1	4	1	1			
Total numbers	23	9	4	9	3	2	2	2	1

When people could identify that they had been to a specialist they said:

- “Got support from my family”
- “The specialist explained the whole condition to me”
- “Yes they told me what was going to happen”

The provision of ongoing care and support	As you get older is it important to stay in your own home?			Your family get good help to support you?			Is it important to get easy ways to travel?			Your family get support when you come to the end of your life?		
	✓	–	✗	✓	–	✗	✓	–	✗	✓	–	✗
Shropshire	28			28			28			28		
Telford and Wrekin	12	2		14			14			14		
Total numbers	40	2		40			40			40		

The provision of ongoing care and support	Is important to see the same doctor?			To get appointments easily?			Do you feel you have enough time talking with the doctors or nurses?			Do you want test results sent to your home?		
	✓	–	✗	✓	–	✗	✓	–	✗	✓	–	✗
Shropshire	28			28			18	8	4	28		
Telford and Wrekin	20			20			12	6	2	20		
Total numbers	48			48			30	14	6	48		

Multiple Conditions

Some people who completed the questionnaire identified themselves as also having other conditions:

Learning Disabilities

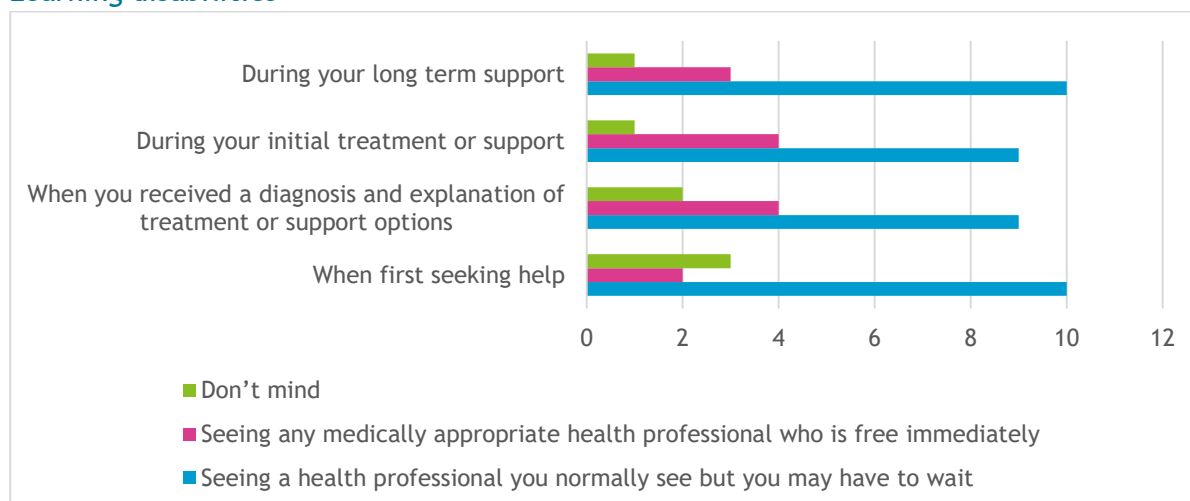
Seven people had additional conditions and six of those felt that it made getting support harder, and one thought it made no difference.

Autism

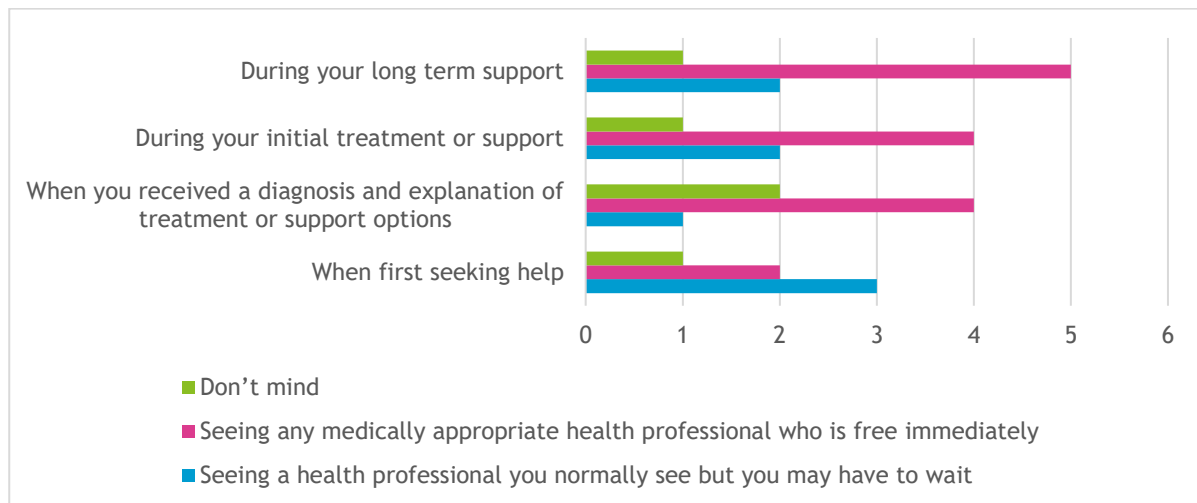
Three people had additional conditions and two of those felt that it made getting support harder, and one thought it made no difference.

What is most important to you at each stage of your care?

Learning disabilities



Autism



Prevention and/or early intervention

Questionnaire responses

Learning Disabilities

When asked about the time people had to wait for their initial assessment or diagnosis five people described it as fast or very fast, two as Ok and three as slow or very slow.

Autism

When asked about the time people had to wait for their initial assessment or diagnosis three people described it as fast or very fast, one as Ok and seven as slow or very slow.

“Young people with Autism, if very severe, will often get help but if less severe or high functioning, then no service is available.

There also continues to be a huge difference between young people transitioning from children to adult services. Prevention and early intervention were identified for young people as a key factor. Putting in services earlier may helped prevent young people becoming an adult with more complex mental health problems.”

[Unmet Needs in Telford and Wrekin, Initial Review](#) Healthwatch Telford & Wrekin

Focus group findings

🟡 ‘What could the NHS do to help you stay well?’

The focus groups highlighted the need for:

- Easy read information
- The importance of the annual health check
- Health workers communicating in an understandable way

Making it easier to make appointments was part of the feedback as was the value of workshops to raise not only health awareness but also awareness of other safety issues, for example crime and fire prevention.

‘Taking Part’ added that “the Expert by Experience (Shropshire) group have fed-back their concerns, which are echoed by their peers in Telford & Wrekin, consistently on health service matters many times in the last few years. Through for example:

- the annual Shropshire, Telford and Wrekin Health and Social care self-assessment Framework
- Government Green papers, e.g. Making Lives Better
- co-production for the Patient Passports and easy read information
- events and campaigns including Health Heart Humour and Hats Off/Ask the Question.

None of the people we spoke with could navigate all the health service processes without significant help/support, even for people who are very independent (i.e. do not have formal health or social care packages of support around them). There is a reliance on informal support, families and friends, but crucially also advocacy groups, peer groups and where available housing associations. As cuts, tighter budgets and contacting criteria impacts there is decreasing support.

So the Experts by Experience wonder and would like to say to the NHS,

“You already have the answers please act upon them.

- Rather than all these expensive surveys and reports use the money to support/maintain and develop the support mechanisms around people with needs, this will have better outcomes for us.
- Help to make sure that our carers are supported and keeping themselves healthy.
- Keep supporting groups and organisations like Taking Part who help many people formally with issue-based and citizen advocacy support. All the staff help informally; we can rely on them for help e.g. reading/understanding letters from doctors/hospitals. Very importantly around prevention work they have helped people to understand the benefits of healthy eating, to having a patient passport, to supporting expert by experiences to represent their peers on important groups such as the LeDeR (NHS England Learning Disability Mortality Review) programme steering group and many things in between.

Work like this is getting lost and must be the same all over the UK, the EE group feel that they are being forgotten often lumped together with people who are autistic or have mental health issues.”

Summary

Our findings show that what matters most to people in Shropshire, Telford & Wrekin who have learning disabilities and autism is:

- **Clear communication with health workers**, including easy read information.
- **Consistency of health care professional** e.g. the same doctor

What would you do?

- This was highlighted by all members of the focus groups, both those with learning disabilities and those with autism. However, those with autism who filled out the questionnaire indicated that it was less of an important factor in the various stages of their support.
- **Compassion**, understand that I am a person not a ‘condition’ and do not let my disability overshadow other potential conditions.
- **Easy access to appointments**
- **Carers who I know and I can trust**
- **Timely, on-going, reliable information and advice for carers**
- **The importance of the Annual Health Check**

A theme raised by respondents with autism indicated the importance of seeing a specialist at the initial stages of assessment.

Supporting people with long term conditions (e.g. diabetes, arthritis)

Overview

Many people are affected by having long-term conditions - which will impact on their physical and / or mental health - with some people facing the challenges of dealing with two or more conditions at the same time. [Research by the Health Foundation](#) found that around one in 12 people have four or more conditions - an estimated 4.7 million people in England.

For example, low back and neck pain is the greatest cause of years lost to disability, with chronic joint pain or osteoarthritis affecting over 8.75 million people in the UK. **Over 30 million working days are lost due to musculoskeletal (MSK) conditions every year in the UK and they account for 30% of GP consultations in England.** 1.7 million children have longstanding illnesses, including asthma, epilepsy and diabetes, and England lags behind international comparators in some important aspects of child health.

Compared with the general patient population, **patients with severe mental illnesses are at substantially higher risk of obesity, asthma, diabetes, chronic obstructive pulmonary disease (COPD) and cardiovascular disease** and make more use of urgent and emergency care.

Over the coming decade, the NHS will inevitably need to look after more people, with greater needs, as a result of our growing and ageing population. For example, **the number of people over 85 is projected to increase from 1.3 million to 2 million** and they will need appropriate support. The growth in average costs with age is projected to increase at a faster rate, due to the growing number of long-term conditions and particularly multiple conditions.

The Long Term Plan identifies a number of inter-related approaches:

- Use of digital technology;
- Service redesign (the right care at the right time in the optimal setting);
- Supporting independence and self-care.

Some of the approaches relate to specific conditions whereas others will be applied more generally.

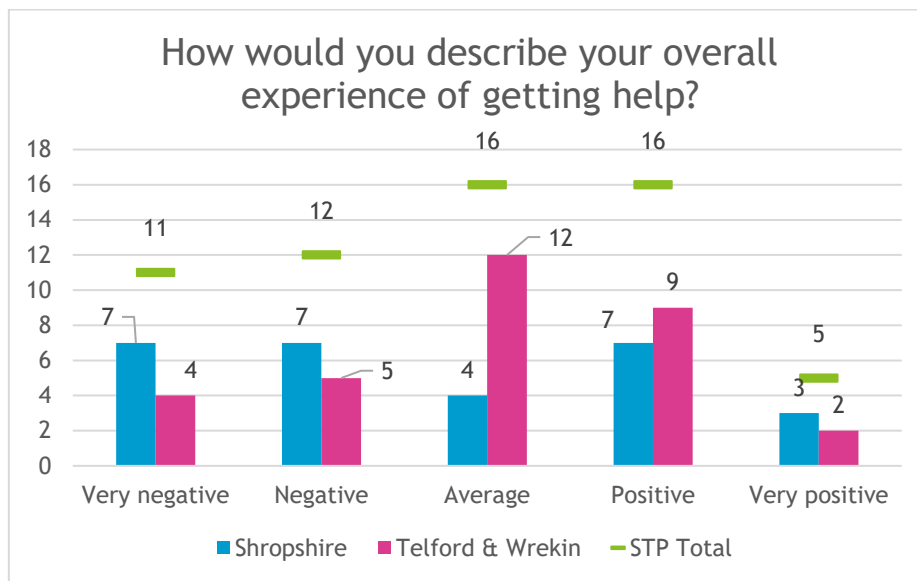
Long Term Condition Questionnaire

Respondents

In the questionnaire about NHS support for specific conditions 62 people, 29 from Shropshire and 33 from Telford & Wrekin, told us about their experiences of services for their long-term condition.

Overall Experiences

Getting Help



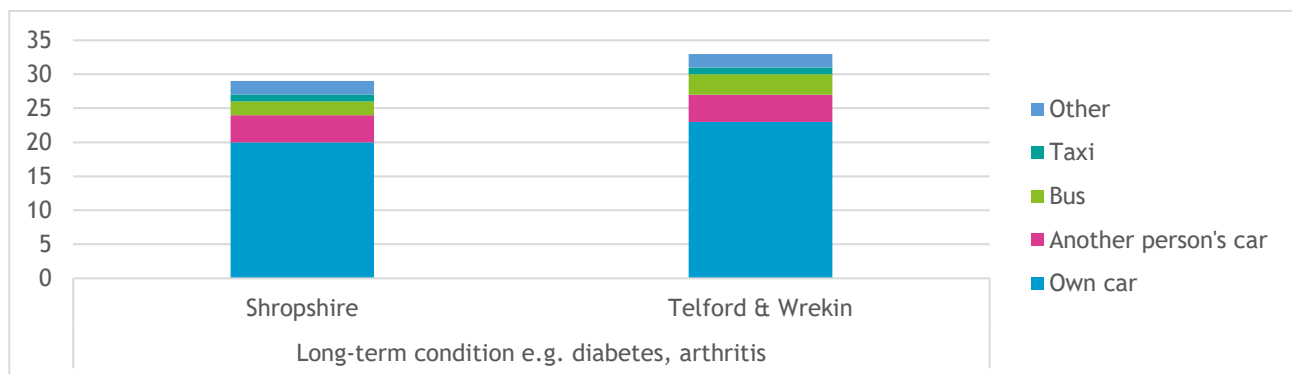
“The Shropshire Enablement team’s help was invaluable as it provided many insights in how to manage the condition in practical ways as well as how to cope with the situation mentally. They also, at a later date, gave me help to learn how to use a computer in a way I could manage as I’m unable to concentrate for the length of time needed in ordinary classes. Sadly the Team no longer exists I understand...”

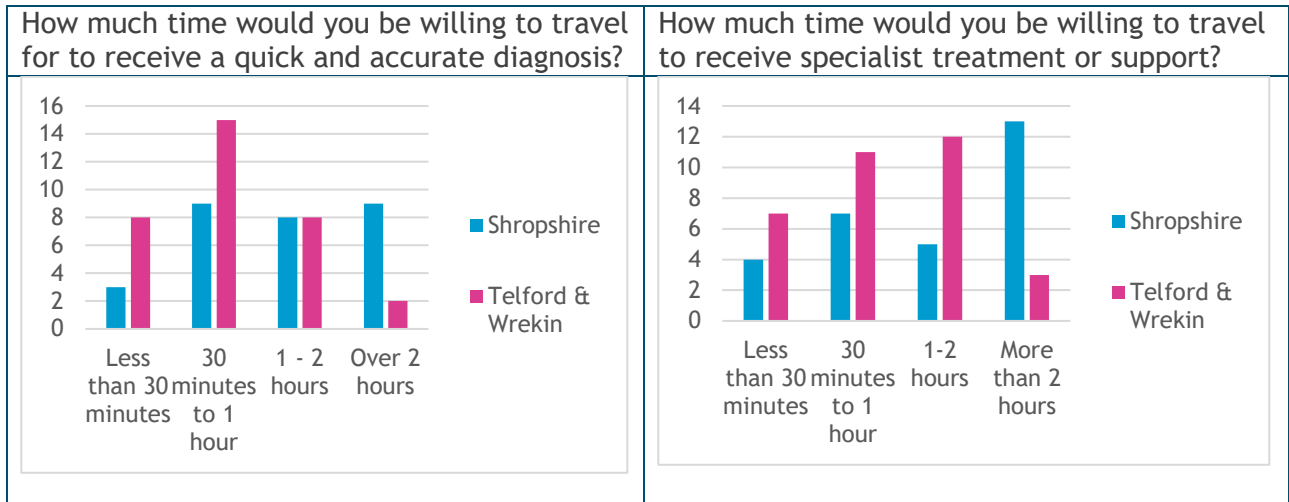
Communications

When asked if people received timely and consistent communication 12 (19%) of respondents felt they did, 12 (19%) they did ‘somewhat’ and 34 (55%) that they did not, four did not answer.

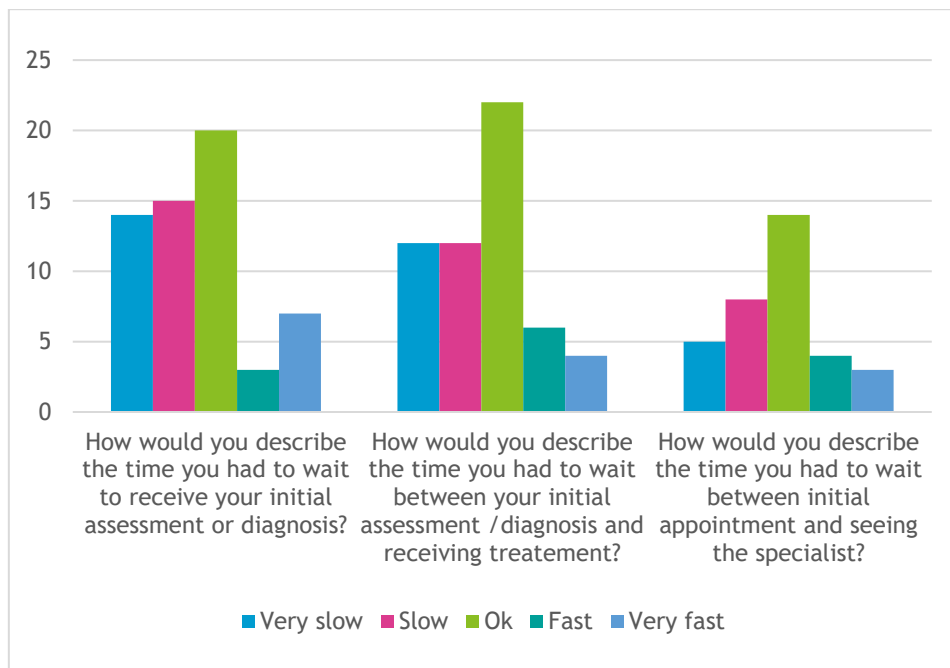
Transport and Travel

Main means of transport



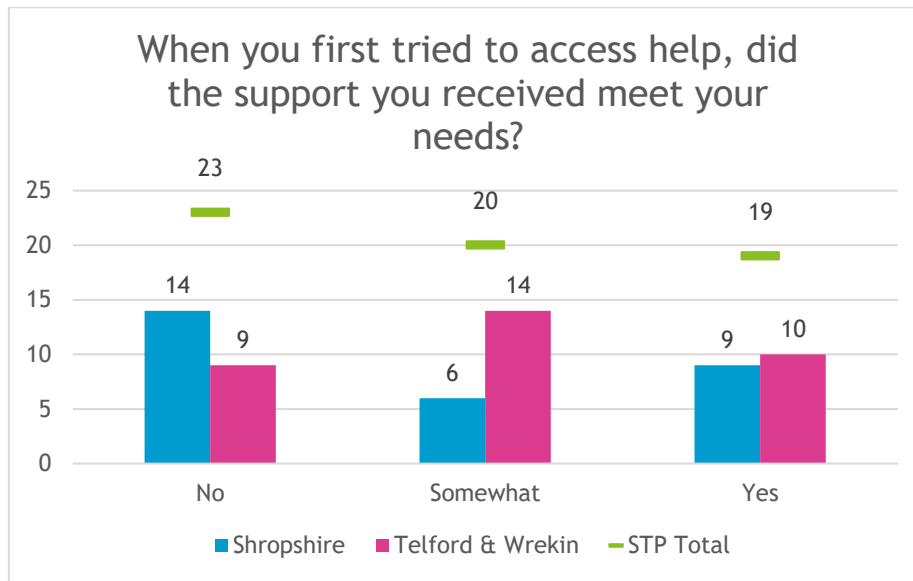


How would you describe the time you had to wait?



“Very quick follow up, due to the diagnosis of diabetes, but this was essential as we had a huge amount to learn in a very short time.”

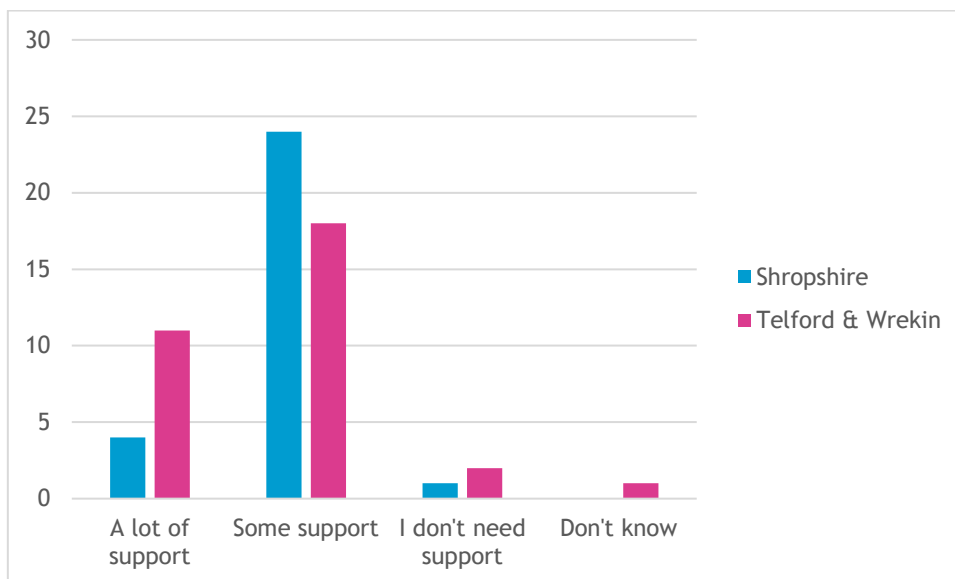
Assessment, diagnosis and treatment



“It could have been improved by more communication, not having to chase for answers and diagnosis. Going through 4 different doctors was pretty frustrating.”

The provision of ongoing care and support

- What level of support do you want the NHS to provide to help you stay healthy?



After diagnosis 10 people found it ‘Easy’ or ‘Very easy’ to access on-going support, 28 found it ‘Difficult’ or ‘Very Difficult’ and 13 said it was ‘OK’.

What would you do?

When asked if the support options offered met expectations, 16 people replied that it did, 11 replied 'somewhat' and 28 replied that it did not.



“Home visits where necessary from GP nurses who understand the condition. (and are your regular ones). Liaise with social services to help with food, cleaning etc.”

Common themes

The responses to questions around the quality of support that respondents had experienced, what they felt could be improved and what they felt the NHS could provide showed some common themes. These themes have been collated to indicate the areas of support that respondents commented on most. A full count of the themes is in [Appendix 2](#) along with the question answers on which they are based (questions 6b, 13, 14, 18b, 19b, 25, 26).

The top five themes were:

1. **Listen to me** (13 respondents), e.g. “GP could and should have paid more attention to what I was saying”, “The rheumatologist I saw didn't listen and talked over me”, “Felt like no one believed me”
2. **Access to specialist services** (11 respondents), e.g. “Replace the missing Parkinson’s nurse”, “Provide more specialists in Shropshire for specialist conditions”, “I had an infection in a joint where my RA was bad but on arriving there [A&E] there was not a Rheumatologist to see only an MSK consultant who had no idea about my condition at all”
3. **Communication with the patient** (10 respondents), e.g. “Shropshire must be the worst authority for lack of communication and care.”, “Sometimes I get letters with results of tests and such and sometimes I don't. It is very inconsistent. I have no “care plan” as such and have no idea how things tie up with one another.”
4. **Continuity of staff** (9 respondents), e.g. “Please can patients with complex long-term conditions be seen by one person so they get to know the person and are quick to notice changes”, “It would be good if you could see the same clinician each time you need advice”
5. **Information and advice** (7 respondents), e.g. “Information on support services / groups would have been useful”, “Education on long term conditions and impact on families”, “I was not told what to expect with on-going condition”

Other themes included: Communication between staff / services and condition review / monitoring.

Neurology ‘Hot Topic’

In September 2017 we focused our engagement efforts to try to understand the patient experience of neurology services in Shropshire. This resulted in the collection of 97 experiences.

The majority of the feedback came from patients with long-term conditions:

- Parkinson’s
- Multiple Sclerosis
- Motor Neurone Disease.

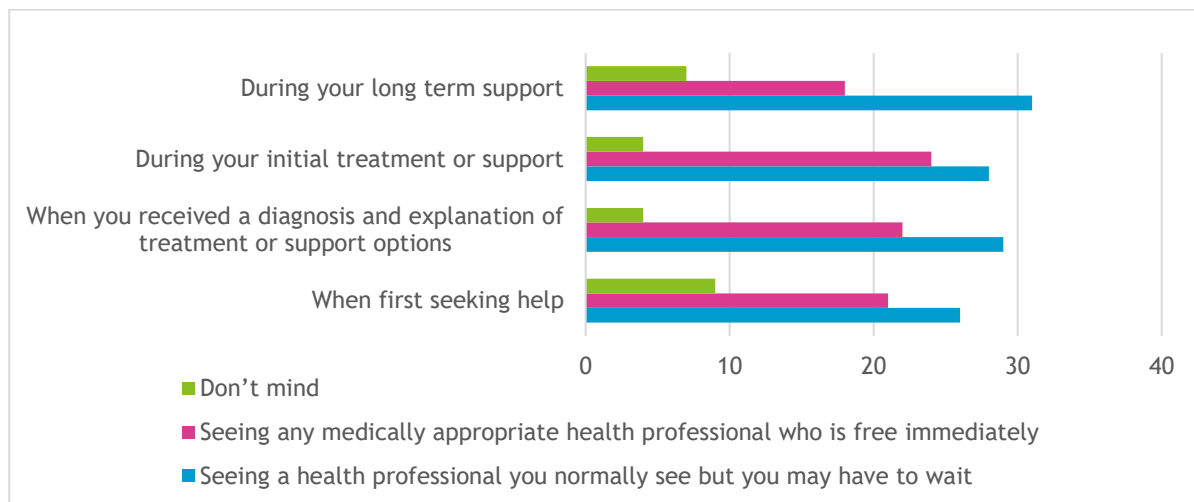
Many of the themes that came through this engagement were the same as those raised in the table above.

[Read More](#)

Multiple Conditions

Just over half, 33, of the people had additional conditions and 19 of those felt that it made getting support harder, six thought it made no difference and three thought it made it easier.

What is most important to you at each stage of your care?



Prevention and/or early intervention

When asked about the time people had to wait for their initial assessment or diagnosis 10 people described it as fast or very fast, 20 as Ok and 29 as slow or very slow.

Summary

Although this group had a larger cohort size it was a very varied ‘catch all’ group and therefore difficult to generalize and therefore summarize findings. However, what is noticeable for people in Shropshire, Telford & Wrekin who are living with long-term conditions is:

- In Shropshire there is a general negative reporting of the overall experience of getting help with most people answering average to very negative. The picture in Telford and Wrekin appears slightly more positive with the majority reporting average to positive experiences. The responses from Telford & Wrekin appear consistently slightly more positive throughout many of the quantitative data answers.
- Difficulties around communication is strong within the free text comments; difficulties with inter- service communication also between the person and professionals helping them. The need for access to specialist services is also high in the free text responses.
- In all phases of support and treatment this group identified it was important to see a health professional that you would normally see.
- The free text comments indicated that a leading theme was that people felt they were not listened to, especially when first seek help.

Improving mental health support

Overview

Mental health problems often develop early and, **between the ages of 5-15, one in every nine children has a mental condition**. Half of all mental health problems are established by the age of 14, with three quarters established by 24 years of age. Prompt access to appropriate support enables children and young people experiencing difficulties to maximise their prospects for a healthy and happy life. While the latest prevalence survey has shown only a modest increase in diagnosable problems since 2004 - from 10.1% to 11.2% - this overall figure includes **concerning rates of mental distress particularly amongst late teenage girls**.

Mental health support features prominently in the NHS Long Term Plan and talks about it being central to the concept of **triple integration**:

- Primary/community care / specialist care

- Physical health / mental health

- Adults' services / children's services

The NHS Long Term Plan builds on the work done in the [Five Year Forward View](#) but sets some important new ambitions and targets.

Importantly it states that there will be investment to support this - **with mental health budgets set to grow faster than the overall NHS budget**, and children and young people's mental health services to grow even faster.

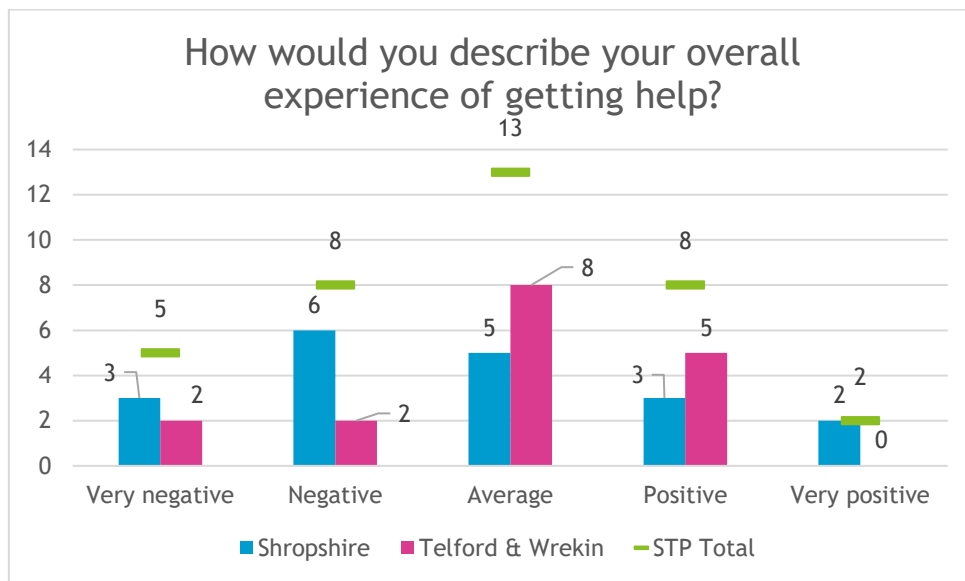
Long Term Condition Questionnaire

Respondents

In the questionnaire about NHS support for specific conditions 36 people, 19 from Shropshire and 17 from Telford & Wrekin, told us about their experiences of mental health support.


Overall Experiences

Getting Help



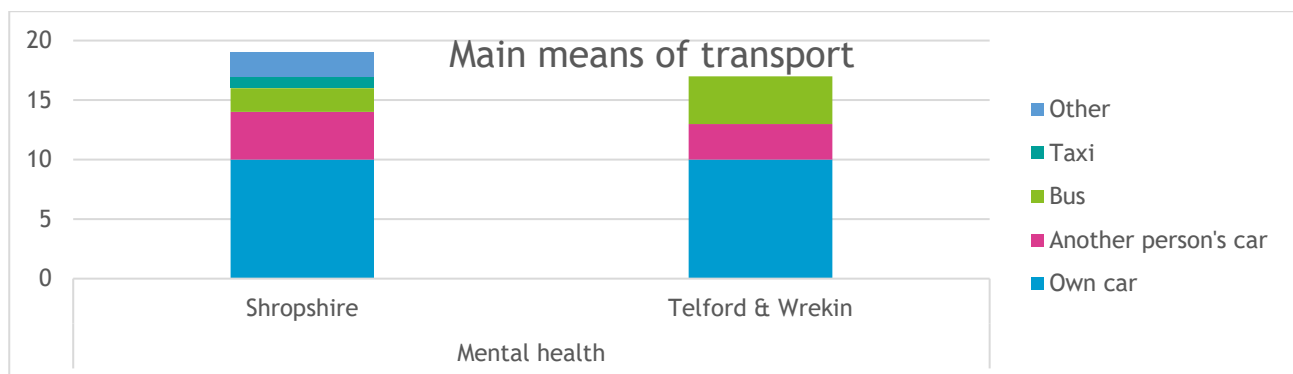
Communications

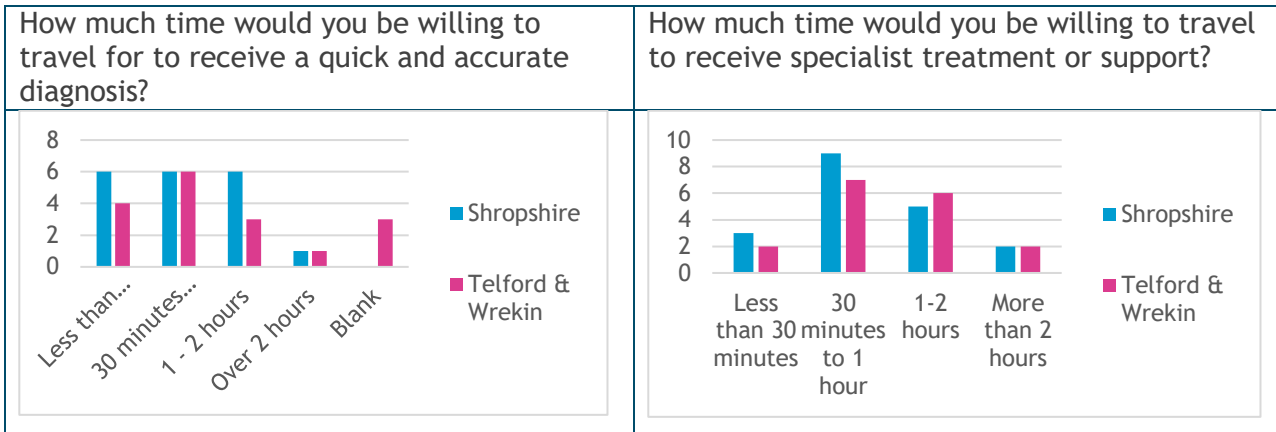
When asked if people received timely and consistent communication 11 of respondents felt they did, nine they did ‘somewhat’ and 15 that they did not.



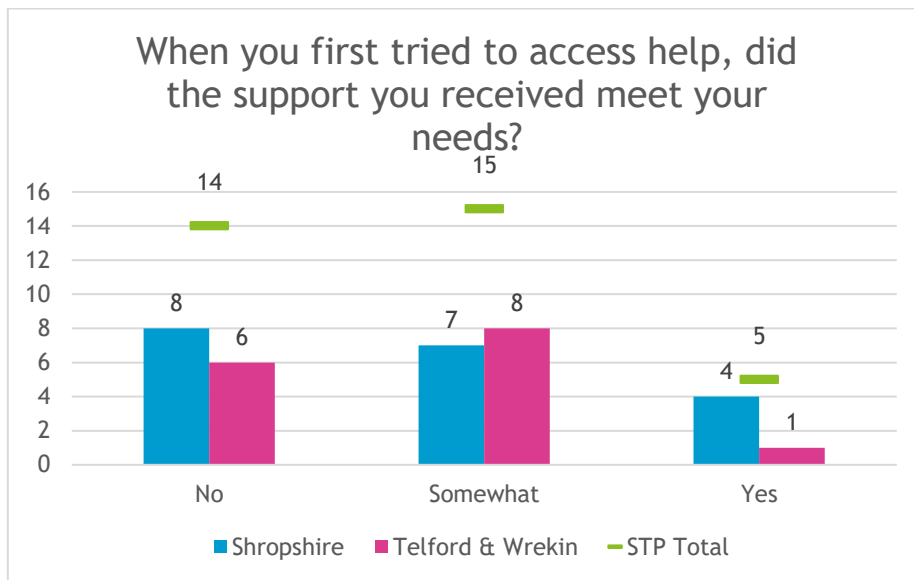
“A lot of mixed communications between professionals. Support offered was wrong and made me worse and was judged.”

Transport and Travel



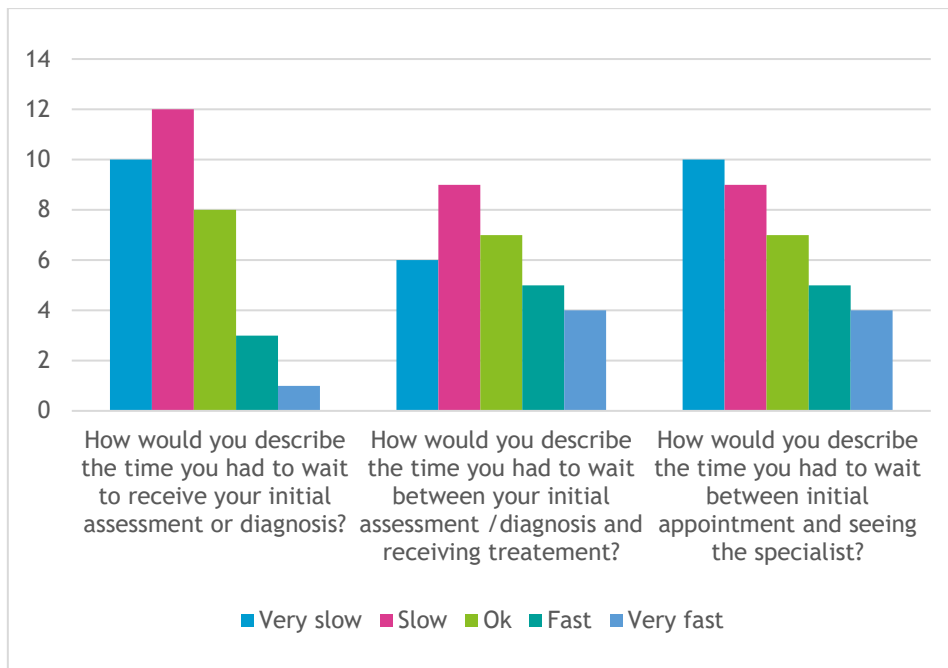


Assessment, diagnosis and treatment



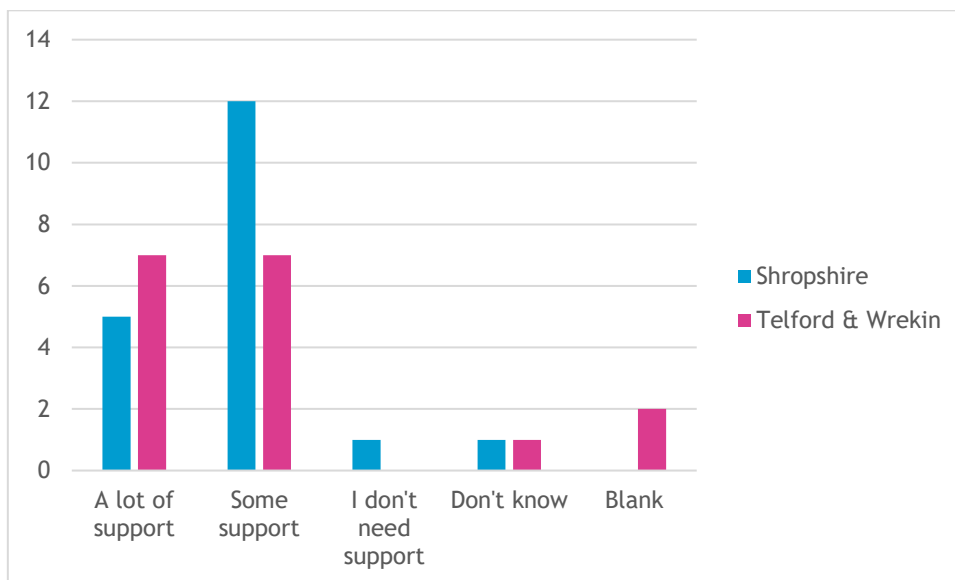
“I attended 1:1 CBT and was not offered any other kinds of support. It would have been good if there was a free App that I could have been recommended or a free book”

How would you describe the time you had to wait?



The provision of ongoing care and support

What level of support do you want the NHS to provide to help you stay healthy?



After diagnosis seven people (23%) found it 'Easy' or 'Very easy' to access on-going support, 15 (48%) found it Difficult or Very Difficult and nine (29%) said it was OK.

When asked if the support options offered met expectations, six people (17%) replied that it did, 14 (39%) replied 'somewhat' and 16 (44%) replied that it did not.

Common themes

The responses to questions around the quality of support that respondents had experienced, what they felt could be improved and what they felt the NHS could provide showed some common themes. These themes have been collated to indicate the areas of support that respondents commented on most. A full count of the themes is in [Appendix 2](#) along with the question answers on which they are based (questions 6b, 13, 14, 18b, 19b, 25, 26).

The top themes were:

1. **Access to specialist services (5)**, e.g. “There needs to be a central task force who connect all the services and provisions together. Someone central that the families can access at all times”, “I had telephone support while I waited for the help”, “Face to face contact with a specialist”
2. **Information and advice (4)** e.g. “Clear information and advice that goes into the right amount of detail for the individual”, “Better information and drop-in points”

Each of the following themes were commented on by three respondents:

3. **Communication with patient**, e.g. “Better communication!! I think that as so many “back office” staff have either been removed and outsourced, (e.g. appointments services) it is not unknown to receive the letter AFTER the actual appointment time!”
- Continuity of staff** e.g. “See the same practitioner who is familiar with my progress.”
- Access to services out-of-hours**, e.g. “My friend attended counselling but found it hard to make appointments with working full time and appointments only being offered during office hours”
- Communication between staff/services**, e.g. “A lot of mixed communications between professionals.”
- Condition review/monitoring**, e.g. “Regular three or four months check-up just to make sure all is well, so not to relapse.”
- Support in the community**, e.g. “GPs need to refer people to the available support groups can offer in the community.”

“There is a big gap in support before people reach acute stage.

There is a real lack of services for people who are not acute but have severe problems resulting in their needs being left unmet. If they are suicidal the people can get help from Mental Health services, but this is time limited.”

[Unmet Needs in Telford and Wrekin, Initial Review](#) Healthwatch Telford & Wrekin

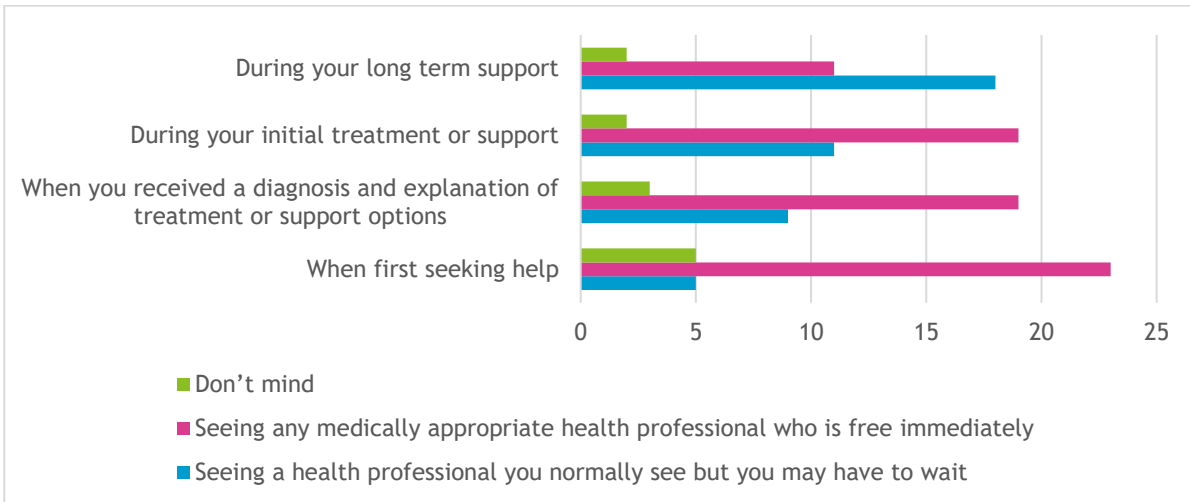
Multiple Conditions

Seventeen people had additional conditions and 12 of those felt that it made getting support harder, one thought it made no difference and two thought it made it easier.



“...as a carer for a mental health patient who has a long and very complex medical/psychiatric history, I would like my needs to be taken into account when deciding my partner’s treatment plan. When she is ill it puts a lot of strain on me as I have heart, bowel and other health problems which are totally ignored by the mental health services”

What is most important to you at each stage of your care?



Prevention and/or early intervention

When asked about the time people had to wait for their initial assessment or diagnosis five people (11%) described it as fast or very fast, eight (27%) as Ok and 22 (57%) as slow or very slow. Two (5%) were unsure.

Summary

With a small number of respondents, it is difficult to generalize and therefore summarize findings. However, what is noticeable for people in Shropshire, Telford & Wrekin who are living with mental health needs:

- There is a general negative experience of the overall experience and quality of treatment possible due to difficulty accessing initial help, long waiting times, poor communication, and difficulties with accessing on-going support.
- The level of perceived on going help and need of support to stay healthy is high with the majority identifying ‘some’ to ‘a lot’ of support required.
- It is important to see any appropriate health professional when first seeking help, receiving a diagnosis and initial treatment. It was only during the long-term support phase that seeing a health professional you normally see becomes important.



“I think it would be helpful if services understood that many people with mental health issues also work full-time. Having to take time off to attend appointments in the day can add to the pressure you are under (e.g. as a teacher where time off is much frowned upon) and cause you to disengage before treatment is complete or you have attended the recommended number of sessions”

Implementing cancer health and care services

Overview

Survival rates for cancer are the highest they have ever been. For patients diagnosed in 2015, one year survival was 72% - over 11 percentage points higher than in 2000.

Actions in the plan can largely be grouped into four areas:

- Prevention;
- Diagnosis;
- Treatment;
- Patient experience.

The strongest emphasis is on diagnosis as this can have the greatest impact on improving outcomes.

The NHS Long Term Plan sets a new ambition that, by 2028, the proportion of cancers diagnosed at stages 1 and 2 will rise from around half now to three-quarters of cancer patients meaning that 5,000 more people each year will survive their cancer for at least five years after diagnosis.

The plan identifies specific activities around children's cancers because although survival rates for children with cancer have doubled over the past 40 years, mortality has fallen for other conditions and cancer is now the biggest cause of premature death among children and young people aged 5-14 years.

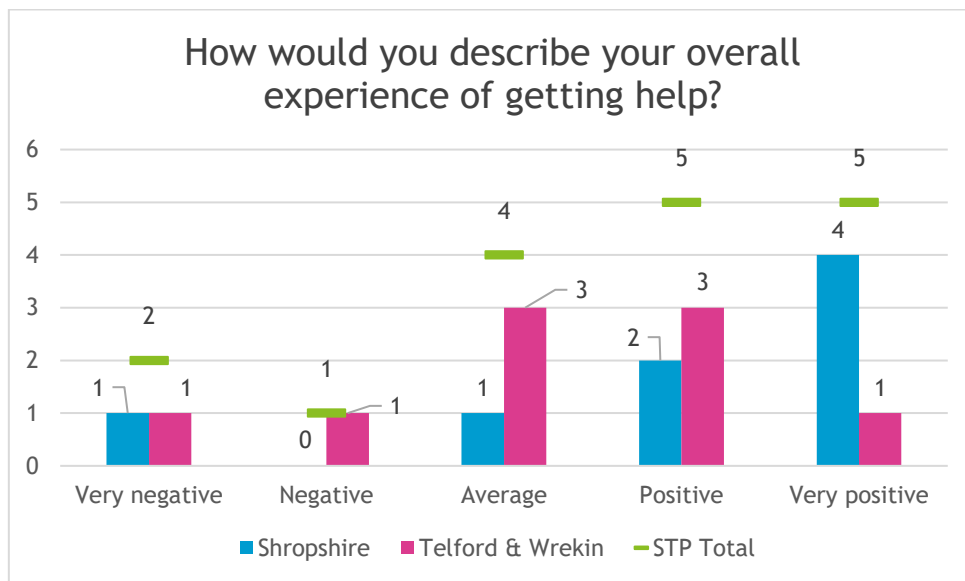
Long Term Condition Questionnaire

Respondents

In the questionnaire about NHS support for specific conditions 17 people, eight from Shropshire and nine from Telford & Wrekin, told us about their experiences of Cancer services.

Overall Experiences

Getting Help



Communications

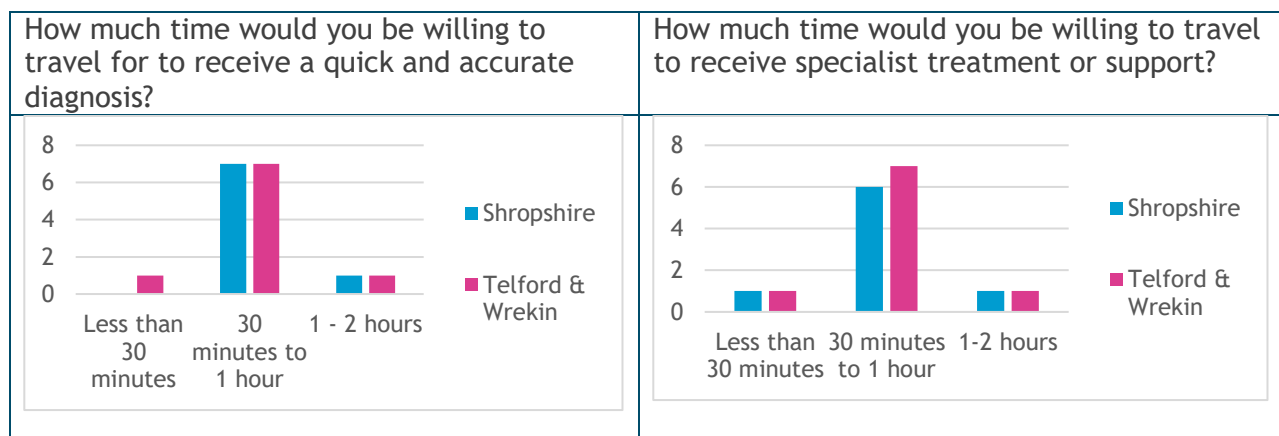
When asked if people received timely and consistent communication ten of the 17 respondents felt they did, five that they did ‘somewhat’ and two that they did not.

Three people commented on problems with communication. Examples:

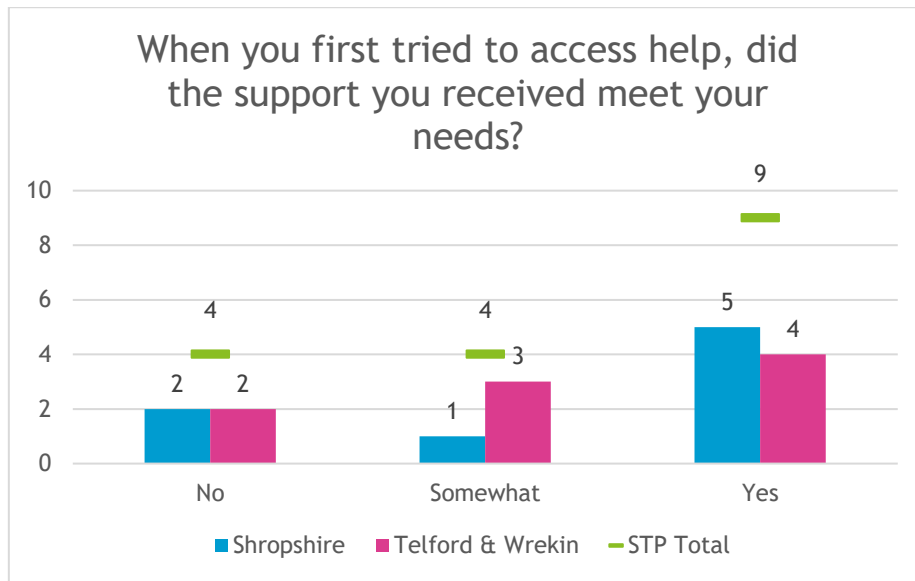
- “Initial diagnosis was not provided carefully enough”
- “At the time was completely overwhelmed by the professional jargon”

Transport and Travel

All respondents main means of transport was their own or somebody else’s car.

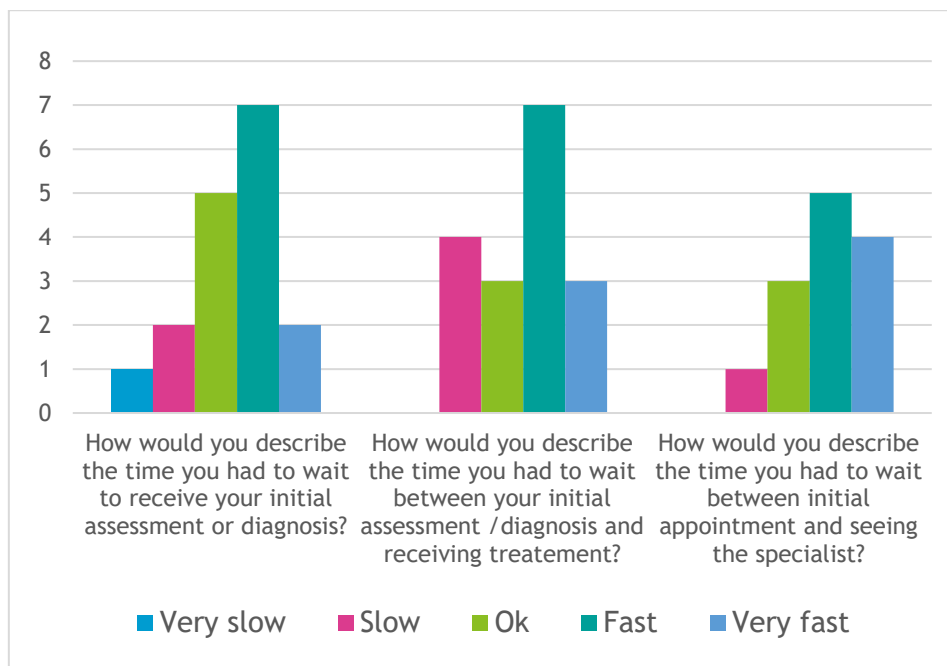


Assessment, diagnosis and treatment



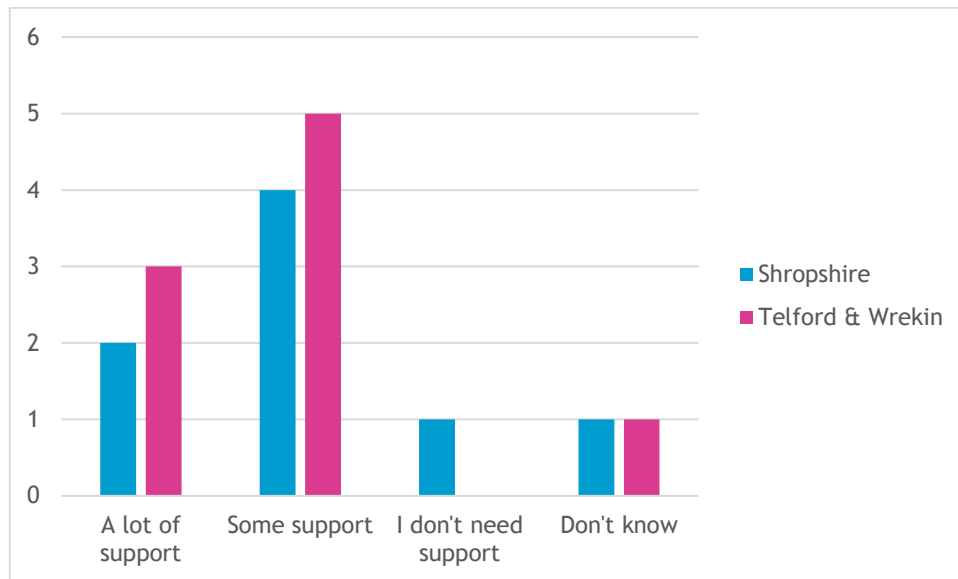
“Brilliant fast acting appointments with referrals biopsies maybe just a phone call from a clinical nurse just asking how we are after everything would be appreciated!!”

How would you describe the time you had to wait?



The provision of ongoing care and support

What level of support do you want the NHS to provide to help you stay healthy?



After diagnosis seven people found it ‘Easy’ or ‘Very easy’ to access on-going support, five found it ‘Difficult’ or ‘Very Difficult’ and three said it was ‘OK’.

When asked if the support options offered met expectations, eight people replied that it did, four replied ‘somewhat’ and four replied that it did not.



“Advice and guidance, reliable information in different formats, access to health professionals when needed but not necessarily a doctor”

Common themes

The responses to questions around the quality of support that respondents had experienced, what they felt could be improved and what they felt the NHS could provide showed some common themes. These themes have been collated to indicate the areas of support that respondents commented on most. A full count of the themes is in [Appendix 2](#) along with the question answers on which they are based (questions 6b, 13, 14, 18b, 19b, 25, 26).

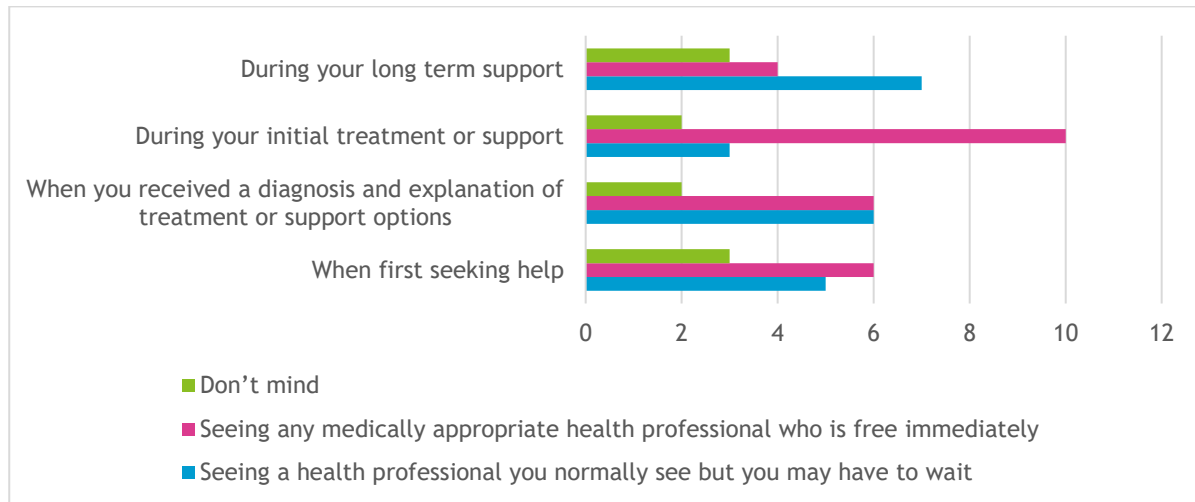
Some main themes identified were:

- Access to specialist services (4 respondents)**, e.g. “Only improvement in my case would be more local to where I live, closer hospitals with gynaecologist should be able to see me through recovery instead of having to travel so far [Stoke]”, “Clinical nurses need to follow up, get in touch, just ask how we are doing!!!”
- Information and advice (2)**, e.g. “Advice and guidance, reliable information in different formats” [would help me stay healthy and manage my condition]
- GP access (2)**, e.g. “Make access to GP easier and be able to see the same GP.”

Multiple Conditions

Eight people had additional conditions and five of those felt that it made getting support harder; one thought it made no difference and one thought it made it easier.

What is most important to you at each stage of your care?



Prevention and/or early intervention

When asked about the time people had to wait for their initial assessment or diagnosis 9 people described it as ‘fast’ or ‘very fast’, five as ‘Ok’ and three as ‘slow’ or ‘very slow’.

Summary

With a small number of respondents it is difficult to generalize and therefore summarize findings. However, what is noticeable as important for people in Shropshire, Telford & Wrekin who are living with Cancer is:

- To be seen quickly by any appropriate health professional during the initial treatment and support phase. The preference for longer-term support, however, is to be seen by a health professional you would normally see.
- Multiple conditions appear to make it more difficult for most people to gain the help they need, however most respondents were satisfied with the overall experience of help.
- Greater access to specialist services.



“It was assumed I was aware of what stage I was in, how my mental health would be effected was not mentioned. Everything felt like it was taken out of my hands to be dealt with by professionals who knew best (of course I understand that but still feel like I was almost rushed through diagnosis and treatment) . I concur they do know best but some self-knowledge and minor input would have been appreciated.”

Heart and lung diseases - prevention, diagnosis and treatment

Overview

Heart and circulatory disease, also known as cardiovascular disease (CVD), causes a quarter of all deaths in the UK and is the largest cause of premature mortality in deprived areas. This is the single biggest area where the NHS can save lives over the next 10 years. CVD is largely preventable, through lifestyle changes and a combination of public health and NHS action on smoking and tobacco addiction, obesity, tackling alcohol misuse and food reformulation.

Respiratory disease affects one in five people in England, and is the third biggest cause of death. Hospital admissions for lung disease have risen over the past seven years at three times the rate of all admissions generally and remain a major factor in the winter pressures faced by the NHS.

Incidence and mortality rates for those with respiratory disease are higher in disadvantaged groups and areas of social deprivation, where there is often higher smoking incidence, exposure to higher levels of air pollution, poor housing conditions and exposure to occupational hazards.

Enabling more people with heart and lung disease to complete a programme of education and exercise based rehabilitation will result in improved exercise capacity and quality of life in up to 90% of patients.

The approach to these issues can be seen broadly in terms of:

- Prevention
- Diagnosis
- Early treatment
- Rehabilitation

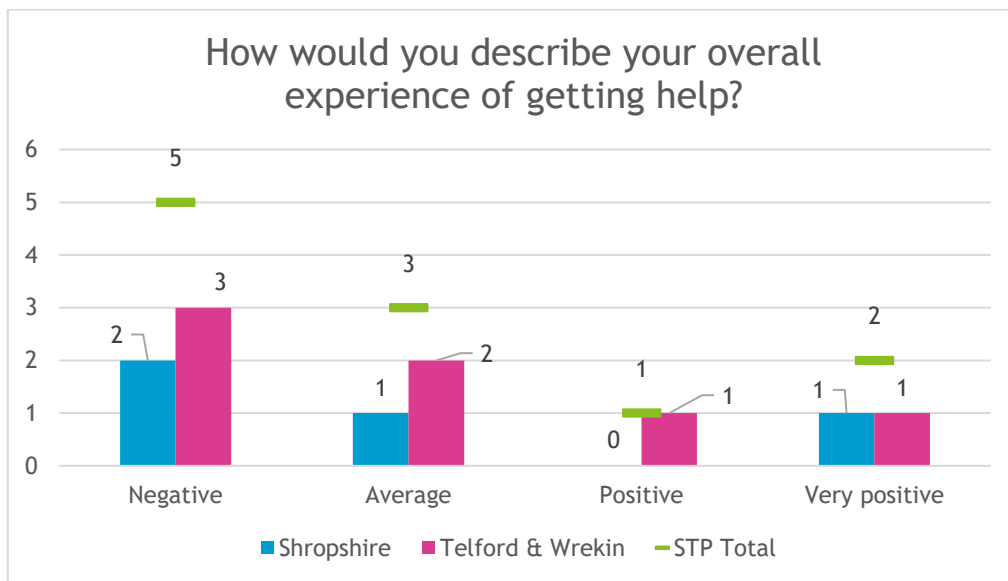
Long Term Condition Questionnaire

Respondents

In the questionnaire about NHS support for specific conditions 11 people, four from Shropshire and seven from Telford & Wrekin, told us about their experiences of Heart and lung disease services.

Overall Experiences

Getting Help

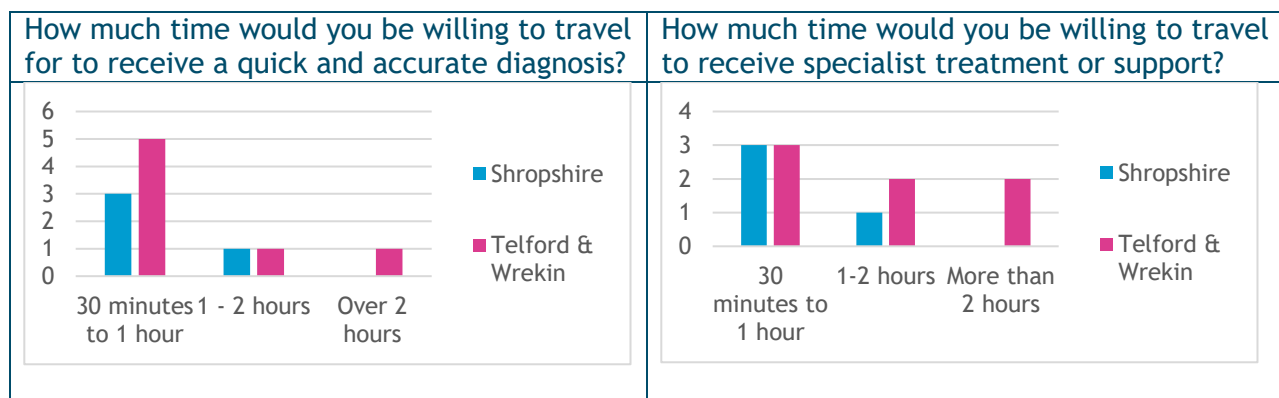


Communications

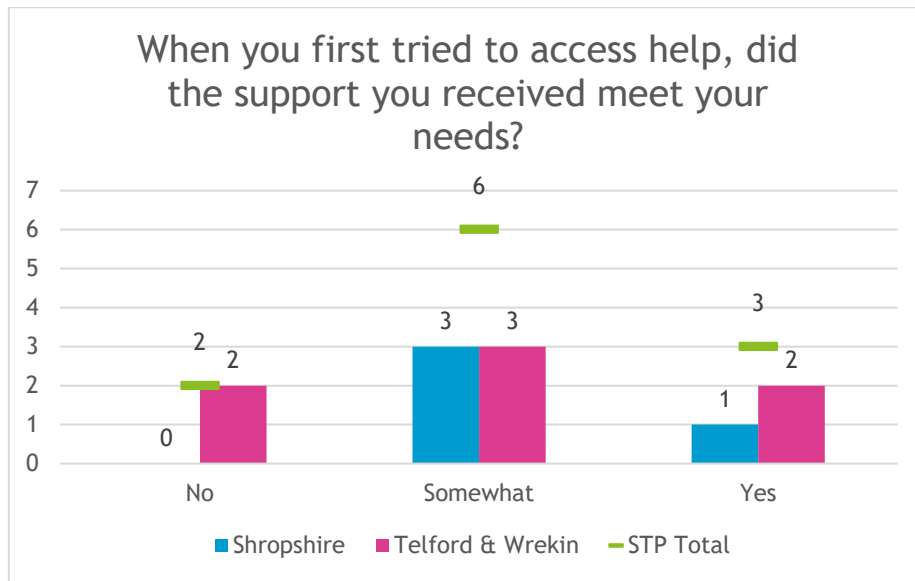
When asked if people received timely and consistent communication one of the respondents felt they did, six they did 'somewhat' and four that they did not.

Transport and Travel

Nine respondents main means of transport was their own or somebody else's car, for one person it was the bus and one the train.

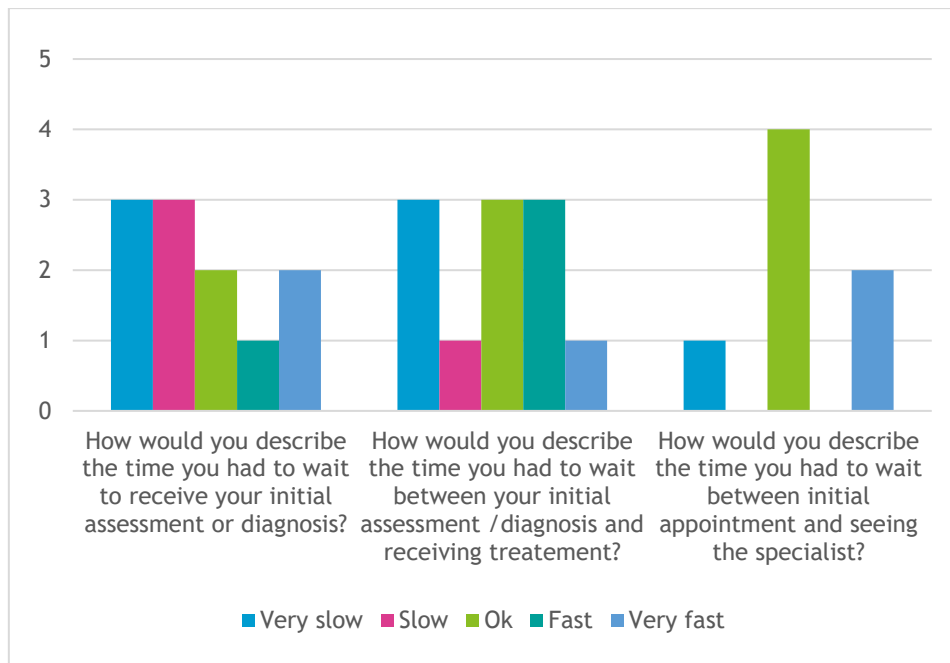


Assessment, diagnosis and treatment



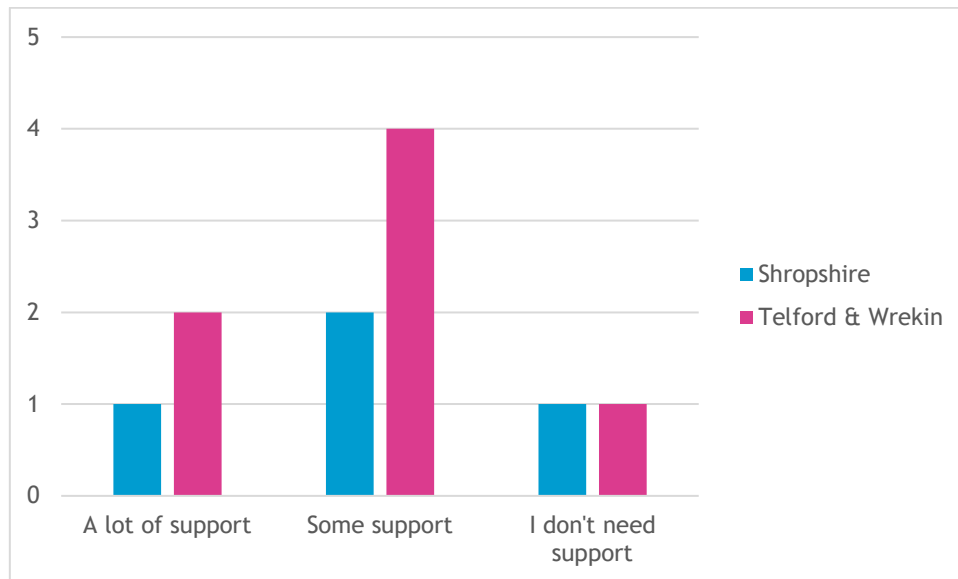
“I underwent tests very quickly saw the Consultant quickly several times. Gave me advice and we agreed along term treatment plan which was acceptable to me and is still working.”

How would you describe the time you had to wait?



The provision of ongoing care and support

What level of support do you want the NHS to provide to help you stay healthy?



After diagnosis three people found it ‘Easy’ or ‘Very easy’ to access on-going support, three found it ‘Difficult’ or ‘Very Difficult’ and three said it was ‘OK’.

When asked if the support options offered met expectations, four people replied that it did, five replied ‘somewhat’ and two replied that it did not.



“Reasonably quick access to my GP, access to local cardiac specialists, enough GPs so we don’t have to wait so long for GP appointments, yearly MOT with cardiac professionals, yearly general health MOT with GP.”

Common themes

The responses to questions around the quality of support that respondents had experienced, what they felt could be improved and what they felt the NHS could provide showed some common themes. In particular:

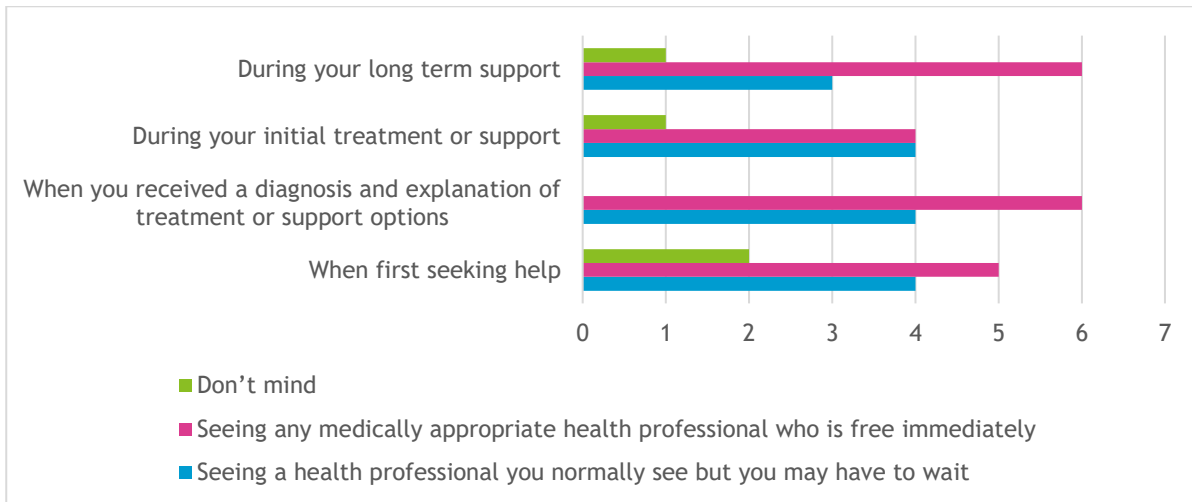
- **Communication with patients** - Three respondents identified this as an issue, e.g. “Shrewsbury [SaTH] communication non-existent”

A full count of the themes is in [Appendix 2](#) along with the question answers on which they are based (questions 6b, 13, 14, 18b, 19b, 25, 26).

Multiple Conditions

Nine people had additional conditions and of those five felt that it made getting support harder, three thought it made no difference.

What is most important to you at each stage of your care?



Prevention and/or early intervention

When asked about the time people had to wait for their initial assessment or diagnosis three people described it as ‘fast’ or ‘very fast’, two as ‘Ok’ and six as ‘slow’ or ‘very slow’.

Summary

With a small number of respondents, it is difficult to generalize and therefore summarize findings. However, what is noticeable for people in Shropshire, Telford & Wrekin who are living with heart and lung disease:

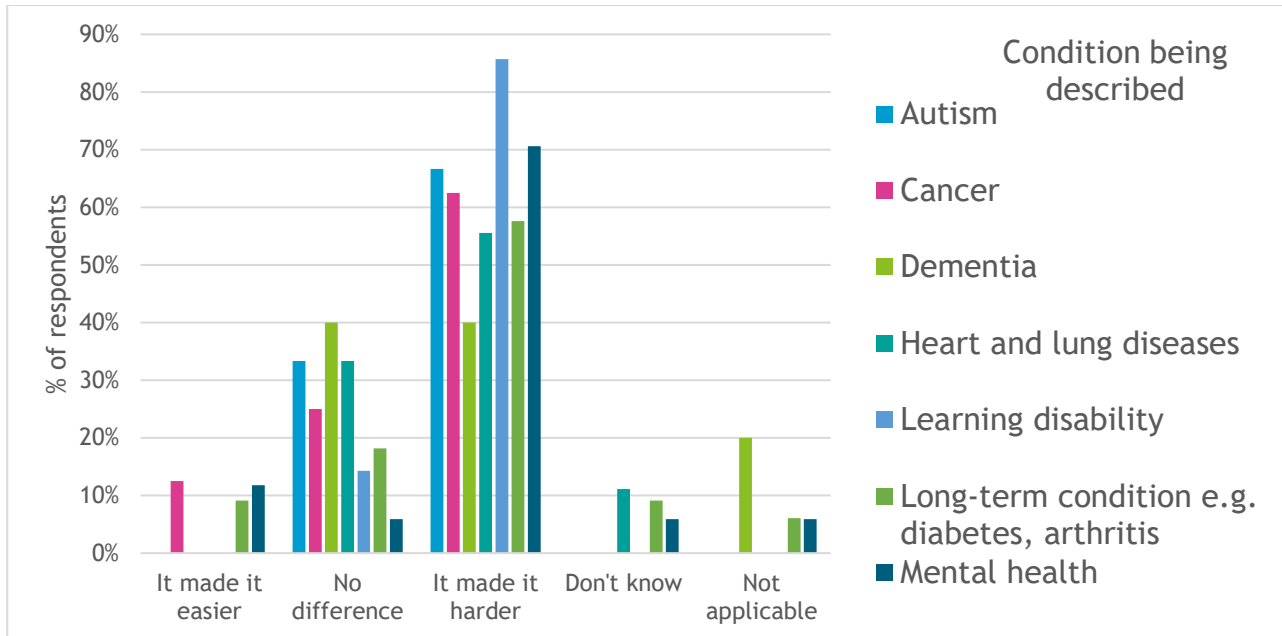
- There is a general negative experience of the overall experience and quality of treatment possible due to difficulty accessing initial help and Ok to poor waiting times in all phases of treatment.
- Multiple conditions appear to make it more difficult for most people to gain the help they need
- Although a small number of respondents many raised communication as being of importance



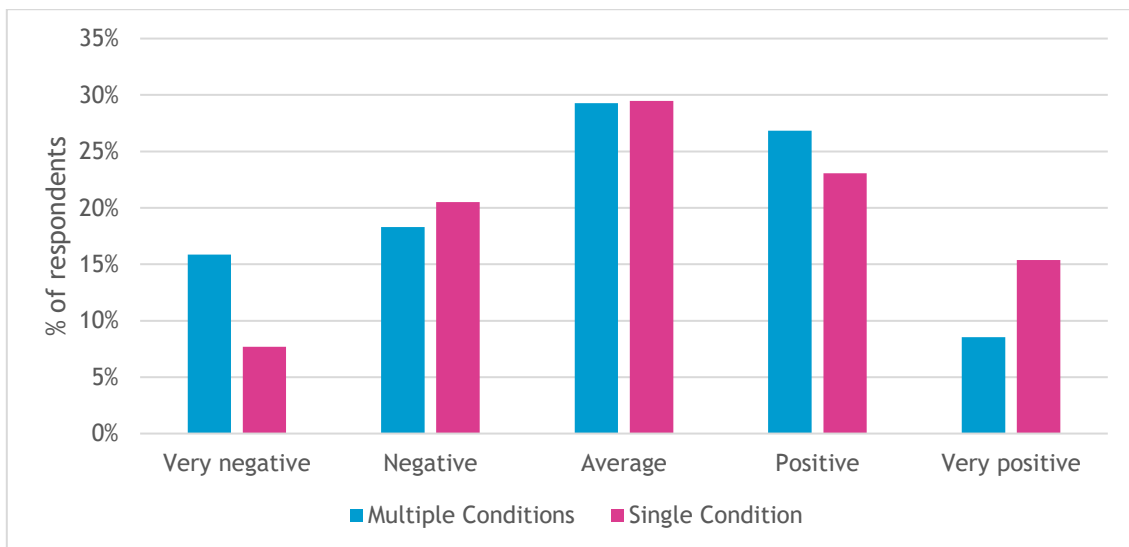
“Maintain funding for specialist centres and education to the public, that to maintain high standards and competences, sometimes traveling a distance to a service is in their interest to get the best treatment and support.”

Overview of the experience of those with multiple long term conditions

Those with multiple conditions described the experience of seeking support for more than one condition at a time as follows:

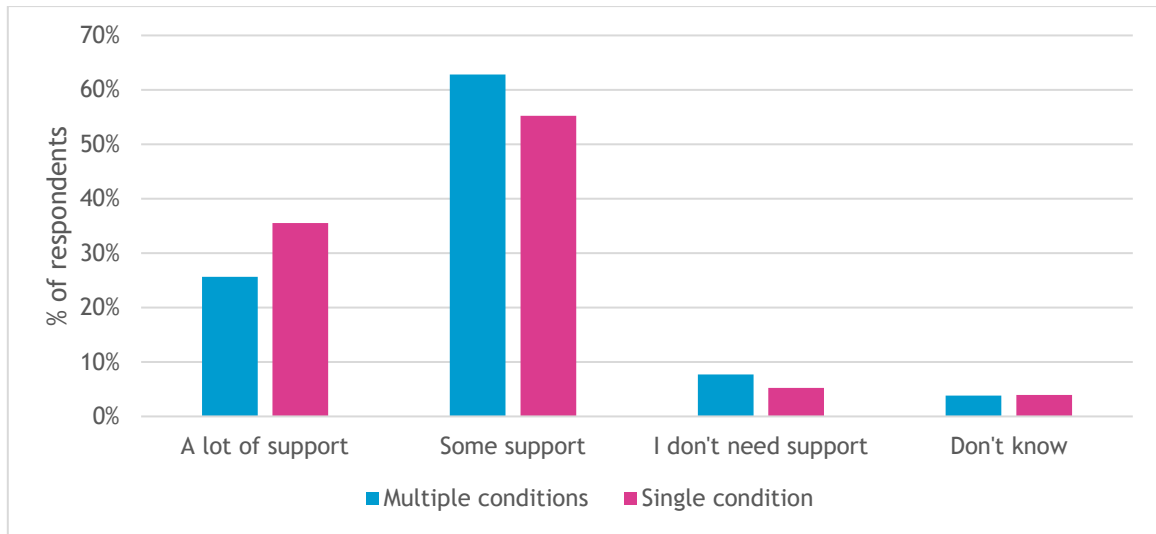


How would you describe your overall experience of getting help?



The significant difference between these two groups appears between the numbers who found the experience very negative or very positive.

What level of support do you want the NHS to provide to help you stay healthy?



Engaging people in health service design and delivery

Healthwatch Shropshire and Healthwatch Telford & Wrekin did not directly ask people how they would like to be engaged in health and care service transformation going forward. We did ask people for their feedback on our approach to this piece of work, e.g. the engagement methods. A representative from Sight Loss Shropshire asked the STP to conduct further focus groups with people with a sensory impairment to ensure their views and ideas are considered when producing the local Long Term Plan.

Feedback regarding the ‘What would you do?’ public events was overwhelmingly positive with 13 people from Telford & Wrekin giving their feedback and 12 people from Shropshire. All 13 respondents from Telford and Wrekin either ‘agreed’ or ‘strongly agreed’ that they found the presentations interesting and the table discussions good. The 12 respondents from Shropshire gave a greater range of response, however nine (75%) either ‘agreed’ or ‘strongly agreed’ that the presentations were good and 11 (92%) said the discussions were good and they had enough opportunities to participate. Twenty people across both events ‘agreed’ or ‘strongly agreed’ that it had helped them to understand the local issues.

One attendee at the Shropshire event told us:

- “I found it useful to speak to fellow attendees who in their various ways all had concerns about what’s happening to services and the ability of primary and community healthcare services to cope with demand - however ‘differently’ they are able to work. The key message that emerged from our group was the need for ‘honest’ communications from healthcare commissioners and providers”

Comments from attendees at the Telford & Wrekin event included:

- “The talk was interesting - I await the action”
- “Table discussions - everyone on my table actively took part and made contributions. It was a good relaxed atmosphere.”
- “Good to see Shropshire and Telford & Wrekin Healthwatch working so well together”

Limitations of this piece of work

The questionnaires

Comments received by both Healthwatch about the questionnaire and its limitations will be shared with Healthwatch England as part of the review process, e.g.

- “Every question in this survey is a ‘leading’ question. It does not suggest that the survey was piloted very well!”
- “This survey form became confusing once the question regarding more than one condition had been answered”

We also received feedback regarding the Easy Read versions of the questionnaires.

Attendance at the public events

In this STP area there has been a range of public engagement over the last few years, in particular regarding the reconfiguration of the acute hospital Trust under 'Future Fit'. This may have impacted on the limited response from the press to our press releases to promote the public events.

Healthwatch also believe that the previous experiences some people have had of being asked their views on services and their redesign directly impacted on the number of people willing to respond to this piece of work, in particular the on-line questionnaires and public events. Some people have expressed their frustration to both Healthwatch that in the past that they have shared their views with services and commissioners and then they have not seen any evidence that they have been acted upon or the services they have used, valued and given feedback on, have been changed or cut anyway.

Methodology

General Questionnaire Qualitative Data

Analysis of the response to the following questions:

- Q3b) If there was one more thing that would help you live a healthy life, what would it be?
- Q4b) If there was one more thing that would help you manage and choose how the NHS support you, what would it be?
- Q5b) If there was one more thing that would help you retain your independence and live healthily for as long as possible, what would it be?
- Q6b) If there was one more thing that you think needs to change to help you to successfully manage your health and care, what would it be?

Three members from Healthwatch (2 Telford & Wrekin and 1 Shropshire) worked together to order the comments into themes. Themes were developed as the data was read, titles to describe the theme and it's parameters remained flexible until all data was considered and discussed. Some themes had sub-categories where there was a strong similarity between particular issues mentioned. Data within each theme was then reconsidered as a final check that it sat correctly within the allotted theme.

Numbers of comments from Telford & Wrekin (T&W) and Shropshire (S) within each theme were recorded. The overall numbers of data strings within each theme were counted allowing a ranking of the most mentioned themes.

LTC Questionnaire Qualitative Data

A similar approach was taken with the qualitative data in questionnaire 2 however the questions asking for contextual information were quite similar so there was less distinction between the answers to each question. To reduce the recording of repetition the answers to questions 6b, 13, 14, 18b, 19b, 25 and 26 were considered together.

Acknowledgements

Healthwatch Shropshire and Healthwatch Telford & Wrekin would like to thank

- **Taking Part** for their work on the section concerning the support for people with learning disabilities and autism
- Chair, Shropshire, Telford and Wrekin Dementia Action Alliance
- Shropshire, Telford & Wrekin STP Communication and Engagement Team
- Telford Carer's Centre
- Age UK
- Alzheimer's Society
- Mayfair Centre
- Highley Dementia Football Group
- Midlands Partnership Foundation Trust Memory Service

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