healthwatch Shropshire

healthwatch Telford and Wrekin

NHS Long Term Plan

Shropshire, Telford & Wrekin

Engagement report - Appendices

Contents

Appendix 1: Questionnaire 1 - people's general experiences of health and care services

1) Do you consent to Healthwatch using your responses?

- Yes (If yes, go to Q2): 283
- No (If no, go to end of questionnaire): 0

2) Pick the area that best describes where you live

- Shropshire: 167
- Telford & Wrekin: 116

Having what I need to live a healthy life

The NHS isn't just there to help you when you're ill, but to support you to live a healthy life too. Tell us what you think local services could do to help you stay well.

3a) Rate how important the following things are to you when it comes to living a healthy life:

Rate how important the following things are to you when it comes to living a healthy life:
Easy access to the information I need to help me make decisions about my health and care
The knowledge to help me do what I can to prevent ill health
Access to the help and treatment I need when I want it
Professionals that listen to me when I speak to them about my concerns
For every interaction with health and care services to count; my time is valued

Easy access to the information I need to help me make decisions about my health and care

	Shropshire	Telford & Wrekin	Grand Total
Not important	1		1
Neutral	9	1	10
Important	37	36	73
Very important	116	76	192
Blank	4	3	7
Grand Total	167	116	283

Having the knowledge to help me do what I can to prevent ill health			
	Shropshire	Telford & Wrekin	Grand Total
Not important	1		1
Neutral	6	5	11
Important	42	30	72
Very important	113	76	189
Blank	5	5	10
Grand Total	167	116	283

Access to the help and treatment I need when I want it			
	Shropshire	Telford & Wrekin	Grand Total
Not important at all	1		1
Neutral	1		1
Important	31	12	43
Very important	128	102	230
Blank	6	2	8
Grand Total	167	116	283

Professionals that listen to me when I speak to them about my concerns			
	Shropshire	Telford & Wrekin	Grand Total
Not important	1		1
Important	24	13	37
Very important	136	101	237
Blank	6	2	8
Grand Total	167	116	283

For every interaction with health and care services to count; my time is valued			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important at all	**2**		**2**
Not important	**3**		**3**
Neutral	**5**	**13**	**18**
Important	**45**	**23**	**68**
Very important	**107**	**76**	**183**
Blank	**5**	**4**	**9**
Grand Total	**167**	**116**	**283**

3b) If there was one more thing that would help you live a healthy life, what would it be? [free text]

Summary:

Themes raised in the answers.	Number of responses			
	Shropshire	Telford & Wrekin	Total	Rank
Access to treatment and services	34	12	46	1
Example comments: • “short waiting times”, • “Access to help & treatment when I need it”, • “Access to a specialist nurse”, • “get a kidney” (15 of these specifically mention GP surgeries)				
Life style choices	16	10	26	2
Example comments: • “**lose** weight”, • “willpower”, • “more free time…”				
Physical activity	8	6		
Example comments • “cheaper access to sport facilities”				
Advice & support	12	12	24	3
Example comments: • “Better clarity from NHS about what support is available after diagnosis”, • “…supporting me when I am on the right track”, • “ability to tap into shared experiences and support when needed….” • “ better mental health support”				
Communication	13	5	18	4
Example comments: • “knowing how to differentiate between the misinformation fed to me by the media…” • “better communication about preventative tasks and health checks”				
Resources, Training & Research	10	4	14	5
Example comments: • “..A way to measure my Blood Glucose levels without having to prick my fingers”,				

• “ understanding from all health professionals of mental health”				
Nutrition	4	8	12	6
Example comments: • “lower prices for healthy food” • “dietitian to help with nutritional needs”				
Quality of services provided	8	3	11	7
Example comments • “improvement in mental health service” • “a fair allocation of funding…”				
Person centred focus	3	2	5	8
Example comments • “access to more holistic cheap programme” • “to see one person who sees me as a whole person…”				
Non-specific comments	**1**	**2**	**3**	**9**
Transport to services	1	1	2	10
Example comments • “Better public transport…”				
Environmental	0	1	1	11

Comments:

Timely access to information and to be able to speak to someone as soon as I need to (e.g. faster access to GP or NP appointments face-to-face or by phone) I would really like to be able to email my GP or Nurse Practitioner if I have a question rather than wasting an appointment. Otherwise it is so easy to Google the question and be given the wrong information or advice.
Access to help and treatment I need. Not travelling 26 miles to my nearest A&E. Not having to wait 3/4 weeks for a GP Appointment.
Access to reliable information on internet
Information about voluntary groups in the area who offer much needed and valuable to support to people in the community
Calorie and ingredient details on fast/convenient foods and restaurant meals
To see one person who sees me as a whole person, who could understand my needs therefore I could have the correct care at the right place at the right time. It’s not just Care it’s the tools to ensure I can look after myself to live a healthy lifestyle.
Lower the prices of fitness activities and fresh foods
Getting an appointment with GP when you need it, not in 3 weeks time.
more responsive services from the NHS however to prevent and assist with self-help/needs the social services need to play a bigger role and much faster and responsive service to people’s needs their lack of addressing individuals care needs and health issues results in strain on the NHS services many of these issues and incidents would not become so bad if the social services were better organised more responsive and effective plus have better resources not so widely distributed geographically.
More regular check-ups. The Smear test is not available to people over 70.
Having better access to GP if I needed it
Lose weight.

A GP having the time to think about my symptoms (none have the time) and being able to request the appropriate tests (labs won't do tests if patients within reference range).
Use of technology for people to map and monitor their own chronic conditions, such as high blood pressure, without increasing burden on GP practices. Currently only one scheduled health check per year and a lot can go wrong in a year.
Keep active
easy to understand information as I am dyslexic and am sometimes unable to understand what I am reading
The speed of response
Look at directing and paying for people to use preventative activity. Focus on exercise, nutrition, the arts for mental health. more resource into community activity
More effective screening
Better communication between NHS organisations - shared patient records!!
Better Clarity from NHS about what support is available after diagnosis
Access to health professionals via Skype
Time to relax.
Knowing how to differentiate between the misinformation fed to me by the media and what is truthful.
Access to help and treatment when I need it.
More help with diet advice re allergies or getting allergy diagnosis
Have support from multi-disciplines to make a more rounded decision, i.e. medication, named doctor, specialist in health, practitions, counsellors, physios under one roof or at least within a small geographical area
Out of hours care and an email / telephone advice line
A two yearly review of health for all over 60 A five yearly review for health under 60 Why, to check drugs, quite often as people get older they get more and more drug added on which sometimes diminish effectiveness AND with allocated time slot , patients/ Drs can discuss diet , exercise, mental health and agree on goals to achieve to improve health The abandonment of well women/men clinics removed our ability to become partners in our heathy journey
regular exercise
To have the tools available for me to look after myself, I'm finding it so difficult seeing different allied health staff who don't notice or do anything about my complex needs not wants. I want to be able to be as active as I can be but for the last year that hasn't been possible.
Improvement in mental health services.
Free access to exercise advise
Easier access to GP appointments or advice from my GP surgery

Cheaper access to sport facilities.
Speed - not having to wait so long to have treatment and to discuss results when it could be something serious.
Access to health care programmes and fitness
More accessible sexual health facilities (clinics) - outside of normal working hours. - Options to book appointments rather than walk in and wait in a room full of people you may know Better yet - having this accessible at our local GP practice
Healthy products/ dietary (gluten/lactose) being more affordable
Quicker access to GPs - new out of hours service is the right direction
Up to date advice the NHS always appears to be a long way behind the curve
Being able to see the same GP who would know me and my health
Having the services commissioned to help me live well with my condition. For example, Shropshire does not have adequate pain management services. I have a chronic pain condition and I'm having to pay privately to see a consultant in Staffordshire. This isn't acceptable. Recently the pain services, apart from physiotherapy, have been decommissioned form the Robert Jones and Agnes Hunt. I work with the CCG in a voluntary capacity. I have a good general knowledge and background of the NHS and health economy. I know how to navigate various pathways, however I cannot get the right services to support my chronic condition in Shropshire.
I think the above covers the bases.
Shorter waiting times
More money available to train and support the medical professionals who look after me and my friends and family so that they too are looked after and not burnt out by having too many patients to see and look after. Look after them, train them well and they in turn will look after us.
Is it fat or sugar which is bad? When I was younger is was fat so I stopped having butter etc. Now it's sugar help!!
A fair allocation of funding around the country - rather than the list code lottery which exists at the moment.
Get rid of the CCG go back to doctors making direct referrals to consultants The CCG is a waste of time and needs scrapping it is has created numerous none productive Staff who are doing unnecessary none productive jobs
Easier access to GPs , dentists, opticians, podiatrist etc.
Fully operational hospital with a 24/7 A&E and Gold Star standard cardiology service in my local hospital
Improve standards (including CQC rating) within Telford and Shrewsbury Trusts.
More funding for leisurely activities in rural areas to aid with psychical and mental wellbeing and better management of the mental health services in Shropshire.
For me it would have to be swimming. In my opinion there should be a pool in every care home not just the expensive homes.

More GP hours which would enable people to go there instead of A & E. GPs need to return to the way they used to be - work evenings but have the equivalent time off that day. More would become GPs if the stresses were relieved by better hours.
Being able to consult a nurse very quickly instead of waiting weeks to get to see a doctor if I'm not sure how serious or not my condition is.
Willpower
Nothing I can think of; largely it is up to me, information is fairly readily available.
Feedback from Hospital/ medical centres as to how long I must wait for the help and treatment that I require.
Option for health screening at regular stages
Easy access to health professionals
Cheaper heathy products
Access to Swimming
Treatment when needed
No comments made
Personally, there should be more options for adult swimming sessions at more convenient times
Money to buy healthier items
Better access to physiotherapy sessions as waiting list is too long within the NHS, could private treatment be done on the NHS?
To have someone to listen to what I have to say and for them to talk to me inaway I understand if I don’t understand tell me again.
Being listened to rather than the "the words you have spoken have been filtered by me and translated as something completely different"
Regular contacts with health professionals
shorter waiting times to see my GP
Secure ongoing funding from CCG's for non-statutory organisations that provide ongoing support and preventative activities. This would ensure that other services that support statutory health and care services can put all their effort into people and not fundraising.
Better public transport in order to access fitness services e.g. swimming pools, parks and open spaces, social prescribing events. In Shropshire the Council is proposing to cut our country buses, which will be devastating for old people, parents of young children, young people and the disabled. Neither will they be able to access clinics and medical services. unless they are very very local, i.e. within walking distance - pretty difficult in rural areas.
Put systems in place to employ the wealth of knowledgeable people in every community, on a voluntary basis to support those in need.
Put systems in place to employ the wealth of knowledgeable people in every community, on a voluntary basis to support those in need.

Supporting families with children who have complex needs. Not a lot out there.
To feel more valued when speaking to medical professionals. Supporting me when you are on the right track.
The understanding from all health professional about mental health
Get a kidney
To ensure that the clinicians not only understand what I am saying but I can understand them - the use of our language is very important
Time to discuss the options available for management of long term chronic illness with a relevant professional
Easier access to GP services near me. Hospital and GP services should be free phone numbers not everyone can afford to call and have to wait 20-30 mins to be spoken to
Access to appointments out of hours - specialist care
Better mental health support.
I already live a healthy life, I exercise at the gym everyday, eat healthily and think I look after myself, there are lots of people who don't do this things and may look healthy on the outside but inside they are not. I think people need encouragement to look after themselves, work place gyms, would be a start.
As I'm Type 2 diabetic dependant on Insulin - A way to measure my Blood Glucose levels without having to prick my fingers.
To have health professionals listen and take action on concerns before they are a problem. Too many times have concerns been left and then they turn into life long problems. Where it would cost the NHS less for the healthcare professionals to listen in the first place and treat where possible before it gets worse and more expensive.
Generally less stress/worry about work, family, money, health.
Access to information, help and treatment needs to be available 24x7 not 9-5, Monday to Friday.
Being able to see the same GP who had bothered to learn a little about my condition and who understood that when you live with an ongoing condition, I have a Urostomy, you are an expert.
All GB hospitals and doctors surgeries to be linked so that they share all the up to date information about your health, conditions, medication. Currently it’s too paper based and neighbouring authorities can’t share if you move for example
Knowledgeable professionals to advise options when required
better information and access to volunteer clubs and services for the lonely and seniors who have retired
Less stress
Better diet
Having a consistent pint of communication being with TelDoc is very conflicting and frustrating when you are having to repeat yourself over and over. Everyone should have a consistent contact GP, Social Worker

Don't know
Longer appointment times when required.
None at present. I live a healthy Lifstyle
discounted gym pass
Transport if you don't drive. Easy to call
Better accsess and times to get back to lesuire centres. I enjoyed Aqua Arobics but takes up to much time getting the bus there and back and works out expensive.
Time to partake in activities even walking, work 2 jobs to make ends meet and permanently exhausted
Closer access to Gp/pharmacy services.
More free time to have leisure time and relaxation time.
Healthy Eating advice
Availability of interactive services outside working hours, whether on-line or face to face.
Access to more holistic cheap programme
Clean air
Local sport centre
Easier access to health care 24/7
Ability to tap into shared experiences and support when needed, Education of what is available is vital
Better communication about preventative tasks and health checks
Confidence in the system/s (knowing both Health and Social Care are working together), and being able to access help/advice/non-acute care, locally.
close all the fast food chains
Understanding of ME and the ability to choose a morning appointment as I feel I'll in the afternoons.
Tai Chi classes at an easily accessible place and in the early afternoon/lunchtime. Better bus service.
Access to a specialist nurse who understands the latest medical research into ME. More GPS
More information on support groups,etc
Merge Health and Social care into one service. Introduce personal care plans with an accountable professional Introduce personal budgets to cover health and social care Bring NHS and Social care back under state control...take out the private and fragmented services that are costly and unaccountable. Ensure everyone has access to food, housing and a livable income. Move to preventative health and social care support with early intervention.

Increased awareness of local services It's not enough to put it on the net ! It's also important that information is up to date - many services have lost funding ! Use of supermarkets pubs etc to publicise services ?
Access to a health professional to talk over concerns
Better public guidance
Getting access to GP when needed
For my health to be person centred, holistic approach
Easy access to physical activities/exercise classes during the day time
Lower prices for healthy food
Dietitian to help with nutritional needs
Free gym memebership
Easy access to all my medical records.
Greater support in areas such as mental health and counselling.
Opportunities for activities that promote wellbeing e.g. gardening, walking, pets, social co-operative interaction
Easy access to information
Increased availability of preventative services in the community. Also, targeted information on what the key risks are for me i.e. do my individual circumstances (e.g. lifestyle / family history) make me at higher risk of developing particular conditions such as diabetes, cancer, vascular issues, dementia)
Professionals etc need to understand the person- why you do things. Your motivation to change or stay healthy depends on a lot more than having information. It depends on your social situation- if all your peer group like drinking you may not wish to change because you will perhaps not be part of that group. Some people can't afford to live any other way. Stop telling people off like they were naughty children treat them with respect adult to adult
Money - austerity has impacted on wages and that has lead to economic stress and a consequent impact on mental health and wellbeing, access to healthier choices, holidays, leisure facilities etc.
Good information, tell us things, explain
Lower waiting list times.
Access to help and treatment might not necessarily be "clinical", sometimes it is just to be reassured that the way you are feeling/pain you have is normal.
To understand a medical condition after an appointment and know what options I have and who to turn to when I need further information on the issue and if need support that it would provided quickly as some long term condition support to function when you live on your own
Services between all the local medical establishments that I have to go to are joined up and seamless.
The ability to have more access to resources

Regular screening and tests eg cholesterol. I would be happy to pay for these which give peace of mind
An online diary system that allows me to record my health, which is also available for health professionals to view confidentially. EG blood pressure readings, sprains, diarrhoea, migraines, falls, etc.
An online diary system that allows me to record my health, which is also available for health professionals to view confidentially. EG blood pressure readings, sprains, diarrhoea, migraines, falls, etc.
I am okay. I get support from my sister. Carers need good support so they can carry on supporting.
I have a very good doctor (Shrewsbury Marsden) so that's the difference.
Being able to get a appointment at the doctors surgery. And not being told I don't need one by the receptionist
Access to timely GP appointments or alternative advice. I do use pharmacists, but what about those little bits in between that are a little too complex for a pharmacist but you have to wait a month to see a GP?
Better GP services including holistic care.
I think that some of the long term issues (such as weight gain/loss) are more complicated that the local GPs generally have a handle on, Making sure that the front line services have the most up-to-date but reliable information is important. In addition, doctor's need to listen. I was told once when I had severe headaches (hormone-related) that it couldn't be the pill. I went off the pill on the advice of a friend who is an alternative practitioner and the headaches got much better. Secondly, after telling a doctor about all the high fibre food that I was feeding my young daughter to help with constipation, he gave me a list of high fibre foods. It was suggested to me by a friend that perhaps it was something that she was eating rather than something that she wasn't. She went off dairy, much better. Please Listen and Stay up to date.
Free access for over 60's to local authority fitness centres.
Being kept up to date with policies ideas decisions etc and patient participation.
Easier to access doctor appointments, you don't always know weeks in advance that you will need an appointment.
I lead a healthy life
We need Kidderminster Hospital to be re-opened as an A and E and General Hospital-it would help healthcare enormously in our area, and definately save lives. The nearest Hospitals in our area , Shrewsbury ,Telford and Worcester are all struggling and   under great strain, through shortages of staff and too many people to deal with. Kidderminster - , had a superb and recently refurbished General Hospital, serving the large Town and the outlying areas......The Hospital is built, it is big , it has good parking-it had been refurbished and extended just before it was shut as a Hospital some years ago now and a new Hospital was built in Worcester ....but now just provides some X-Ray, scan and minor injuries service. we need that Hospital as well. Dr Brian Taylor campaigned long and hard to get it NOT to close, because it was needed.....AS WELL AS -the new Hospital in Worcester, which has proven to be true. IT is a Hospital which is all set up, it just needs some investment now and staff and could serve the local town and outlying ares and take the strain off Worcester Royal, which is often in the news for not perfoming well, when in actual fact, I feel very sorry for the staff, they are always the ones that get

the blame, when it is staff shortages and lack of investment , and the downgrading of Redditch Hospital, has meant many patients flooding to the already struggling Worcester Royal. My neighbor next door, had a heart attack in his Garden he was in his early 60s-he is now 74 and his wife knows that if he hadnt been able to get to Kidderminster General (before it shut its doors) he would not be here- he would have died, if hed had to make the nearl 1 hour journey to any of the outlying Hospitals. I do hope someone will consider my suggestion- as many believe it would definitely relieve the 1 hour away Hospitals, and be there for the large population of Kidderminster and outlying areas, which is why it was built in the 1st place !!!! Many Thanks for giving me the chance to air an opinion-I do have another one which may help the NHS as well...why not do staffing " in -House"...instead of paying agencies a fortune for staff...just a thought , along the lines of making Efficiencies and economies-which always help financially strained situations. We now have a great investment (at last) from the Govenment, lets build an NHS that we can be proud of, and Re-opening the large general Hospital in Kidderminster-would certainly improve patient services and lead in times for A and E and surgery- I really hope it could be considered-it would make a big difference out here in rural Shropshire and in the large Town of Kidderminster. By the way- I also think Hospital car parking fees, should be "scrapped"-they are extortionate-and I really feel for people who have to visit a loved one who is ill, and it costs them a fortune, that they often cannot afford !! All the very best with it all, and I do hope that me comments, can be considered.
To be able to go for walks.
Easier access to the GP of my choice.
Clear up to date information which is accessible
Clear up to date information which is accessible
To be able to get a doctors appointment

Being able to manage and choose the support I need

When you are unwell and need support or treatment for your condition you need to be properly informed to make choices about what works best for you. Tell us what local services need to do to make this a reality.

4a) Rate how important the following things are to you when it comes to managing and choosing the support you need:

Rate how important the following things are to you when it comes to managing and choosing the support you need:
If I have a long term condition I decide how the NHS spends money on
Choosing the right treatment is a joint decision between me and the relevant health and care professional
I make the decision about where I will go to receive health and care support
I should be offered care and support in other areas if my local area can't see me in a timely way
I make the decision about when I will receive health and care support
My opinion on what is best for me, counts.
Communications are timely

I have time to consider my options and make the choices that are right for me

If I have a long term condition I decide how the NHS spends money on me			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important at all	2		2
Not important	4	5	9
Neutral	37	21	58
Important	62	36	98
Very important	52	50	102
Blank	10	4	14
Grand Total	**167**	**116**	**283**

Choosing the right treatment is a joint decision between me and the relevant health and care professional			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important at all	2		2
Neutral	7	3	10
Important	42	24	66
Very important	111	88	199
Blank	5	1	6
Grand Total	**167**	**116**	**283**

I make the decision about where I will go to receive health and care support			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important at all	2		2
Not important	4	3	7
Neutral	22	16	38
Important	67	37	104
Very important	66	58	124

Blank	6	2	8
Grand Total	**167**	**116**	**283**

I should be offered care and support in other areas if my local area can't see me in a timely way

	Shropshire	Telford & Wrekin	Grand Total
Not important	3	1	4
Neutral	18	6	24
Important	65	47	112
Very important	75	59	134
Blank	6	3	9
Grand Total	**167**	**116**	**283**

I make the decision about when I will receive health and care support

	Shropshire	Telford & Wrekin	Grand Total
Not important at all	1		1
Not important	4	2	6
Neutral	38	8	46
Important	57	46	103
Very important	64	57	121
Blank	3	3	6
Grand Total	**167**	**116**	**283**

My opinion on what is best for me, counts

	Shropshire	Telford & Wrekin	Grand Total
Not important at all	2	1	3
Not important	1	1	2
Neutral	22	13	35
Important	60	38	98

Very important	76	61	137
Blank	6	2	8
Grand Total	**167**	**116**	**283**

Communications are timely			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important at all	1		1
Not important		1	1
Neutral	11	3	14
Important	45	27	72
Very important	106	82	188
Blank	4	3	7
Grand Total	**167**	**116**	**283**

I have time to consider my options and make the choices that are right for me			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important at all	1		1
Not important		1	1
Neutral	7		7
Important	56	38	94
Very important	96	76	172
Blank	7	1	8
Grand Total	**167**	**116**	**283**

4b) If there was one more thing that would help you to manage and choose how the NHS supports you, what would it be? [free text]

Summary

Themes raised in the answers.	Number of responses			
	Shropshire	Telford & Wrekin	Total	Rank
Person-centred approach	17	14	31	1
Example comments:				

• "involved in decision making..." • "..listen to me..." • "professionals to have the time..."				
Choice	8	4		
Example comments: • "access all information...", "...access the service I choose", "...so I can make the right decision for me"				
Suitable support	5	4		
Example comments: • "physio to help...", "availability of suitable individuals..."				
Communication	18	11	29	2
Example comments • "learn how to communicate more efficiently..." • "timely communications..."				
Research & Info	9	6		
Example comments: • "data on hospital performance", "good information"				
Local services to meet local needs	8	7	15	3
Example comments: • "Don't close accident and emergency in Telford" • "to maintain our local service at Princess Royal Hospital" • "it would be beneficial if local commissioners acted on local needs…"				
Resources	13	1	14	4
Example comments: • "To listen to the voice of the people regarding hospital closures", • "being able to have tests… at all ages"				
Staffing	6	1		
Example comments: • "network of appropriate support workers", "more GPs..", "make sure there are enough specialists"				
Easier access to GP/ health professionals/services	7	5	12	5
Example comments • "better GP access", • "GP opening weekend and night", • "being able to access services..."				
Treatment	8	2	10	6
Example comments: • "treatment should not be a postcode lottery", • "quicker reschedules on outpatients..."				
Technology	1	5	6	7
Example comments: • "better digital connectivity", • "better phone system for my GP"				
Non-specific comment	1	3	4	8
Transport	1	1	2	9
Example comments: • "..I regard good transport as a public health issue", • "access to transport as I don't drive"				

Comments:

We should be involved in decision making, our voices should matter.
Understanding of who does what & how
treatment should not be a postcode lottery. All treatments should be available in GB. We all pay the same taxes which fund NHS so all should have access to treatments.
To maintain our local services at Princess Royal Hospital
To listen to the voice of the people regarding hospital closures
To listen to me so together we can come to the right decision.
To have local services not miles away. To be able to get to see a GP in a reasonable time.
To have all the options laid out and explained to me in full so that I can make an educated, well informed decision.
To have access to the right care at the right time wherever it may be.
To be seen locally and not to have to travel especially when you have no car and have to travel on public transport
To be listen to by consultants
Time to listen
The way in which the NHS communicates with me.
The NHS needs to learn how to communicate more efficiently. With it's patients as well amongst it's staff. I have so often come across a situation of the right hand not knowing what the left is doing in this organisation.
The NHS has to have overall control over decisions but the amount spent on people with ME is miniscule compared with things such as MS or Parkinsons. This should change. I feel that we are largely ignored.
That I can access all information and choices
Resources for GPs in order they may spend their time in caring for patients, rather than having to attend meetings in contributing to politically-imposed new 'systems' such as primary care networks, STPs etc which take up so much time within the working day. I do not see that any of these recently-imposed changes/reorganisations are in any way going to increase my (personal) support from the NHS.
research
Rank the services that are available to me and allow me to make a decision based on the competency of that service. For example I should be able to choose a dentist based on performance and patient feedback.
Quicker reschedules on outpatients when doctor is unavailable or has left the practice for specialist areas
Physio to help keep my weight down and help with my mobility.
Patient medical records for those over 60 and longterm medical conditions are assessable by any NHS healthcare professional in the UK. Better and safer care for occasions of hospital admissions A&E or planned for this set of patients.

out of hours advice line, someone to listen who understands and you can talk through the options with
Openness and honesty - if services are struggling with waiting lists let us know Develop clinical pathways and care plans that are shared with people so I know what to expect and who to contact -
None
No suggestions
No going to hospital to be cared for in the community.
No false hurdles to get treatment eg joint replacement.
Network of appropriate support workers.
Network of appropriate support workers.
My employer allowing time to access the services I choose
Most of the above statements are not possible to implement in the current structures because the NHS has been fragmented and underfunded alongside social care. I would change the way the NHS is structured and managed taking out the internal market and ensuring it is paid for from general taxation and managed by clinicians not accountants and politicians.
More trained & professional health care staff available to advise/ direct me the right resources to meet my needs
More provision on localities rather than having to travel to hospital sites
More knowledge about dietary choices to help me manage my diabetes.
More GP's to enable everyone to be seen asp. At present people resorting to A/E's as GP access is so poor
More GPS and specialists in Shropshire. Eg. Neurology. Not having to travel miles for an appointment. A specialist in ME\CFS GPS allowed to make own decisions using their clinical experience, not HAVE to use NHS guidelines.
More gp surgeries in my town market Drayton..... Only one!!!
More availability to be seen on evenings and weekends
Many discussions with consultants are very quick, often taking less than five minute and don't need any physical examination. It would be much more efficient and convenient for both parties if these could take place by telephone or Skype.
Make sure there are enough specialists to make all of the above possible. Make it possible to see a specialist in all areas, eg mental, dementia etc straight away.
Local access to services
Listening to what I'm saying.
Letting me choose the hospital where I want my care. Not just shipping me off to the usual hospital for say heart treatment.
Leaflets to read, ability to record all consultations on my phone to listen to in a calmer frame of mind with family.

It would be beneficial if local commissioners acted on local needs within the parameters of the funding available, rather than acknowledging those needs, but still bowing to national pressures.
It lacks to support me is full of people waiting money doing unnessary jobs when money could be spent on what is really needed
It is no good having a choice as to where to go for treatment if the means to get there isn't available. I regard good transport as a PUBLIC HEALTH ISSUE.
Information
Individual Patients have the RIGHT to determine end of life choice
I want to be listened to and taken seriously
I think the above are important but sometimes the professionals do know what is best for you! Things need to be explained in a manner where everyone understands the wording etc. Certainly consult and give people choices but make sure that they understand what might happen. Also you have to be aware how much things cost and you cannot just have treatment when you want it.
I should be given all the relevant information to me so that I can make the right decisions for me about my own health care including risks of any treatment/surgery or medication.
I should be able to know when I will be treated.
I am not a doctor so my medical needs are not best decided by me. but I should be given the information by the clinicians and then consulted, so I understand what treatment I need and why. they we can discuss the best action to take together. I then want to go to the best place for my needs, wherever that is. if it is not local I am fine with that, I just want specialists who are the best people for me. even if I have to travel. timing is a different thing, wok decides my availability.
Having an influence. When the only influence is privately pay or put up with, then this is unacceptable. I would be willing to verbally expand on this if Health Watch wished to speak to me.
Greater information on local resources and investment in support groups to reduce impact on AE eg DVT services
GPs taking responsibility and being active in referring when they cannot help you, rather than explaining how "its one of things things you just have to live with"
GP opening weekend and nights
Good information so don't walk out of medical centre, hospital etc still wondering what I need to do next
Good information
Full knowledge of what is available for different treatments and there outcomes, in this country and others. Social care and health care linked together so not left feeling alone and stranded.
For professionals to have the time to listen
Following up with wellbeing conversations, for example, if you are aware someone is struggling with mental health or they have previously reached out, there should be a follow up call ensuring they feel thought about.
Face to face meetings

Everything listed is important. Timely communications are important to me as if I have to wait it can add to my anxiety and make me feel worse.
Easy availability of digital communications to manage and arrange support
Easy access to community alternatives instead of acute
Easier access to health professionals
Don’t close accident and emergency in telford
Data on hospital performance
Consultant who knowledge understand and compassion. Not once who disbelieve and tell me to give up work
Consistency in who I see, recent experiences have resulted in my seeing a different consultant on each visit.
Communication, so people at primary care stage, listen. We
Clearer communication. Unfortunately not NHS fault. Needs more funding.
Clear and honest explanations on what my options are are explained
Choice of appointment days / times
Better understanding of the functions of the NHS in relation to links with my GP
Better phone system for my GP
Better GP access.
Better digital connectivity
Better access to community nurses, physiotherapists, podiatrists etc. We need more people who will make home visits or hold clinics locally, especially for physiotherapy and post-hospital rehabilitation. All the money spent on hospital treatment can be wasted without sufficient and timely physio and ongoing rehab, e.g. after strokes, head injuries and broken limbs.
Being local
Being able to see a doctor immediately not a two week wait
Being able to have cancer tests e.g. smear & breast screening at all ages Men to have regular screening
Being able to access services effectively
Be able to see a doctor in my own surgery within a week
Availability of suitable individuals to discuss both short and long term management of my various illnesses
Availability of services locally
As above
Appointment times should be managed/organised better

Access to transport as I don't drive and have no personal transport.
Access to groups related to my condition
Ability to know better what services are available and where
Ability to email NHS teams to ask for support when long term conditions require additional supervision. I would not necessarily need to be seen in a clinic, but would appreciate guidance from NHS professionals
A universal NHS app. Mis-information spreads so quickly it can be hard to tell fact from fiction meaning sometimes people will unintentionally make the wrong choices without realising the harm they are causing. The NHS has multiple apps and information on website to provide accurate information but this can quite often be tricky to find.
A special health worker than can explore the different options available to me. Taking into account the funding that would be required for this.
A reamendment of how the care plan system is handled.
A named professional person to liaise / advise you re services....... Ignorance can result in ill informed decisions or unrealistic expectations
A discussion with an informed practitioner as to all the options available with knowledge of all the pros and cons of each possibility
Communications are timely
Improved feedback from consultants regarding tests and scans direct from the hospital and not having to wait a long time to get the feedback from a GP
Access to most appropriate service and prioritisation of needs with complex problems
Improved co-ordination between services in the community, primary care and secondary care.
Dont assume that everyone wants to accept a treatment. Some treatments have such devasting side effects its not right for everyone.
Working in partnership; access to a range of expertise
make sure support, have time to explain + support / help properly
More avaiability/less waiting times
I would need to have all the information before me, good and not so good so that I can make an informed decision on whether I have treatment and what that will be.
More communication between healthcare professionals. If a person is being seen by more than one consultant why don't they communicate with each other?
As I live on my own with sight issues extra support during illness may be required that is above the normal standard that is supplied
That all the medical professionals I see are aware of my various conditions and treat as a whole person.
Full information from Consultant, at the moment you have to do your own research
Communication in writing or recorded as it is difficult to clearly remember details, which links with ... Opportunity to discuss options with family.

Communication in writing or recorded as it is difficult to clearly remember details, which links with ... Opportunity to discuss options with family.
Don't leave me out because I can't hear. Give me more time (to consider treatment options).
Being listened to - I have spent over 5 years being told I am ill, but no-one wants to diagnose me with anything. Every GP / specialist I go to says I must have a virus, and none listen to me when I say that's what I've heard for 5 years. When I questions the GP's to say "Am I unwell or is this in my head? Either way, I'd love to be treated or helped" they are all convinced it's physically and yet do not act as they do not seem to know where to go, why? It's a strange world we are now living in.
For emergencies, the NHS is great. For routine or chronic conditions, it is sorely lacking. I question the use of agency staff. If you are also paying shareholders and business owners profit, doesn't that take money out of patient care or staff (non doctor) renumeration? Is it really the best way to achieve flexibility?
Not having telephone appointments as the first stage of mental health support, this can be very off putting some someone with a mental health condition and therefore they don't access the support they really need.
I am not a health care professional and I do not therefore know what is best for me with regards to my health, also I cannot deice where I want to take my cure - this is the professional's choice i.e. I assume they will act in my best interest.
A joined up approach to health problems.
The NHS professionals having enough resources to support the foregoing.
The NHS professionals having enough resources to support the foregoing.

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

Our ageing population is placing greater demands on the NHS. We know that people want to be able to look after themselves for longer, and the NHS wants to help you do so.

5a) Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:
I want to be able to stay in my own home for as long as it is safe to do so
My community can support me to live my life the way I want
My family and friends have the knowledge, confidence and power to help and support me when needed
I expect there to be convenient ways for me to travel to health and care services when I need to
I expect that my family and I will feel supported at the end of life

I want to be able to stay in my own home for as long as it is safe to do so			
	Shropshire	Telford & Wrekin	Grand Total
Not important at all	1		1
Not important		1	1
Neutral	5	2	7
Important	22	9	31
Very important	135	99	234
Blank	4	5	9
Grand Total	**167**	**116**	**283**

I want my community to be able to support me to live my life the way I want			
	Shropshire	Telford & Wrekin	Grand Total
Not important at all	1		1
Not important	1	3	4
Neutral	22	5	27
Important	57	44	101
Very important	82	61	143
Blank	4	3	7
Grand Total	**167**	**116**	**283**

I want my family and friends to have the knowledge,to help and support me when needed			
	Shropshire	Telford & Wrekin	Grand Total
Not important at all	1	1	2
Not important	1		1
Neutral	11	5	16
Important	59	31	90
Very important	91	77	168
Blank	4	2	6

Grand Total	**167**	**116**	**283**

I want there to be convenient ways for me to travel to health and care services when I need to			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important	1		1
Neutral	7	3	10
Important	38	30	68
Very important	116	81	197
Blank	5	2	7
Grand Total	**167**	**116**	**283**

I want my family and me to feel supported at the end of life			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Neutral	8		8
Important	29	20	49
Very important	124	92	216
Blank	5	4	9
Not important	1		1
Grand Total	**167**	**116**	**283**

5b) 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? [free text]

Summary:

Themes raised in the answers.	Number of responses			
	Shropshire	Telford & Wrekin	Total	Rank
Resources	15	8	23	1
Example comments: • “easy access to aids and adaptions”, • “investment in community support”, • “financial support to adapt my home if necessary...”				
Support	10	8	18	2
Example comments:				

• "plenty of support", • "support for my family", • "more local professional support"				
Care at home	7	8	15	3
Example comments: • "better community response to home", • "to be at home as long as possible"				
Person Centered approach	11	4	15	3
Example comments: • "to have the time to listen to me..." • "ensure my personal care needs can be met..."				
Making decisions & choice	4	0		
Example comments: • "more information as to what my choices are", "I want to have real choices..."				
End of Life	9	3	12	5
Examples comments: • "feel supported at end of life", • "end of life should be the individual choices"				
Transport	4	4	8	6
Example comments: • "providing more transport for me", • "better public transport..."				
Communication	5	2	7	7
Example comments: • "..I want to be informed of all the services..." • "health to actually talk to everyone..."				
Local services & needs	2	4	6	8
Example comments: • "..what services will be available in my local area..."				
Information	2	3	5	9
Example comments: • "better information..." • "more understanding and awareness of people with mobility scooters"				
Elderly Care	4	0	4	10
Example comments: • "more exercise and activities for aging population", • "improvements and better standards in care homes..."				
Lifestyle	1	1	2	11
Example of comments: • "keeping fit", • "I notice there are a few older people using my gym..."				
Treatment	1	0	1	12
Example comments • "speed of diagnosis then moving on to treatment..."				
Technology	0	1	1	12
Example comments: • "ability to make contact digitally..."				
Non-specific	1	0	1	12
Example comments: • "..it is largely up to me"				

Comments:

Financial support to adapt my home if necessary. Help to maintain my home and garden. My mum was a 'Home Help' in the 1980s. This was such a great service, she would go to someone's home for 2-3 hours, do cleaning, ironing and washing up, help them to get a drink and something to eat and chat to them. This kind of human contact is a life line for people who are living alone or have family who live a long way away.
Not enough money is put into social care and is a worry for aging people and their families. Families are often put in a position of looking after elderly persons with little compensation .
Availability of home care services to meet my needs
I want to have real choices and not just what happens to be available in the area. I want long term funding for projects to run consistently not here for a year or two then disappear to be replaced with the next trending idea for provision. I want investment into community & primary services. I want service planning not just to be based on population density & deprivation indicators but on common sense that rural populations in less dense areas actually have needs as well.
Ensure my personal care needs can be met at times to suit me as a patient and my lifestyle, not be told to have a tea call at 2.30pm in the afternoon when I am active in the community volunteering and would like a tea call at a time to suit me. Organisations need to work together to ensure personal care plans are personal to an individual's needs and requirements
Ability to make contact digitally and know that a response will be forthcoming
I don’t want to be pushed from pillar to post, I just want access to support me to live well for longer.
Access to a vetted housekeeping service to help with household jobs
Again I feel this comes down to the social services involvement a lot of the above need better support from the beginning and this is where the health and social care needs to work better jointly.
Knowing that there are trained health care professionals available for support when conditions change/ deteriorate.
A greater understanding by all on the Value of Home Carers and the savings to the Health and Social Care Economy By this I mean practical Support and an understanding of the Social/emotional and Physiological needs of Carers often overlooked and leads to family breakdown.
Getting good health advice. All members of my family have dietary issues (notably lactose/casein intolerance) but the NHS doesn't seem to 'do' that kind of dietary advice.
See above. More community based services are essential to keep people well and secure in their own homes. More community nurses in particular would reduce the burden on GP practices and hospital emergency and urgent care departments. Regular visits to people with known conditions or vulnerabilities would prevent them reaching crisis point. Expensive to set up properly as services have been cut so much, but much cheaper in the long run.
With supporting older family members I want to be informed of all the services that are available and if the NHS can't provide what we need, then for them to put us in contact with another service that can.
Good diet, active

If I have a terminal illness give me the right to choose when I die
end of life care is poor, personal expreince of how bad this is in the NHS. the hospices however are amazing and experts at this. this care should be replicated in the NHS or the NHS should fund more hospice places, funding the hospice at home model. there is no reason that hospice practice should not be reflected in the NHS. we all deserve a good death and this impacts on families for generations
Adequacy and sufficiency of domiciliary care provision
A realistic expectation of what services will be available in my local area, so that I can choose to move to an area better served if necessary.
Health to actually talk to everyone involved in my care, my experience is once a person in hospital its impossible to get any information or gain information about what I am like when I am well.
Feel supported at end of life
I don't ever want to be kept alive simply because it is possible - that is just a burden on the rest of my family and community.
A NHS that was not stretched to the limit with too few resources, dependant on agency staff (however efficient) and lack of money spent wisely.
Timely support with agencies working together towards my needs.
Agencies who can help without being told, they have a backlog of requests
A specialist professional to bridge gap between health and social care My mum 91 , lives on her own but crisis erupt quickly, over small issues as simple tasks such as phone for Drs app to by 8:30 for same day appointment with dr can be too great a task (acute arthritis in wrist) and overwhelming , causing escalation of complexity of problem..... Can be overwhelming ...... Resolve by phoning a social care person (answerphone)who is able analyse problem and make relevant appointments and report back to person in difficulties
To have the time to listen to me and it being a joint decision
Improvements and better standards in care homes. Elderly are rightly so afraid of going into care homes, which if ran correctly and ethically would be very useful resources.
easy access to aids and adaptations
All the different care agencies/ support to communicate with each other at all times.
Again I would say speed of diagnosis and then moving on to treatment. The longer time you have to wait the more anxious people may feel - which could lead to more problems.
That I feel that I have input and can be included in conversations around care
Ring and ride increased capacity and funding
Freedom form the worry of care costs
There is currently no lead commissioner for dementia at Shropshire CCG. Shropshire is the second most rural county with an aging population which will increase significantly over the next 20 years. One in three people will get dementia and the rest will get a cognitive impairment. Diagnosis rates are not measured in some primary care practices. Very few GP practices are dementia friendly practices. So

there needs to be leadership, strategic direction and accountability for strong dementia services in Shropshire.
Shrewsbury Hospital does have a lead dementia nurse so if you end up in secondary care then the team in the hospital are great. It is the primary care, memory clinics and community services which need to improve.

The NHS needs to learn and respect that many of us are single. They need to respect this, and not pursue to the point of harassment that some of us do not have, or do not choose to include family in their decisions. I have had an incident, where it became obvious during an endoscopy that I did not have someone to take me to and fro to the hospital, and stay with me for the required time after my discharge. Some of us need day beds, where investigations can be carried out, and the required observation time can be undertaken in the hospital. I also firmly believe that well run convalescent facilities should be reinstated. Freeing up hospital beds, but ensuring people can still be cared for efficiently following medical interventions.

Better home care provision

Stop treating patients with Alzheimer's differently to all other medical conditions. All other illnesses receive free treatment or support but with Alzheimer's you are left to it. You are totally dependent on your family, if you are lucky, or you have to use all the savings you have acured during your working life to look after you. NO OTHER ILLNESS IS TREATED THIS WAY, IT IS DISCRIMINATION! OF THE MOST VUNERABLE IN SOCIETY BECAUSE THEY ARE INCAPABLE OF MAKING A DECISION AND ARE TOTALLY RELIENT ON THOSE WHO LOOK AFTER THEM, MOSTLY THE LOWEST PAID. THEY SHOULD BE TREATED EQUALLY WITH ALL OTHER ILLNESSES. THEY CANNOT COMPLAIN ABOUT HOW THEY ARE TREATED.

Continuity of care at all levels. Having cared for and recently lost my mother who was suffering g from a range of chronic conditions, much time was wasted repeating the same information to different departments in the same hospital.

I wNt a return to being valued by the NH S

More help in the home for when I may need it

A system were I can get an appointment to see my GP within a couple weeks instead of the having to wait many weeks for an appointment. Also healthy professional remain open minded to my suggestions and wishes and that I actually may know what I need and want.

Streamline and invest into the process of discharge from hospital to home to avoid bed blocking and unnecessary delays

Correct support from NHS services and easier access to non NHS funded treatments

To have health care nurse to visit for check ups such as district nurses.

Expectation that it is ok to stay at home, more home support, better checks on health care providers, regular district nurse visits to check on you.

Again, no suggestion - it is largely upto me.

Provision of more care and facilities in the home rather than hospital

Better communication of teaching us how to prepare.

Better public transport at reasonable cost

Help for my family at odd times to
Enable them to still work as well as looking after me

Plenty of support

More information as to what my options are.

To have carers who know how to care for me, who respect me and respect my care plan and the times. Do not send carers who cannot fulfill the care plan because of their culture.

Regular health checks

Joined up thinking between services - public transport at affordable prices goes a long way to supporting health and well being. Shropshire Council are proposing cuts to bus services, increased fares on park and ride and abolition of concessionary fares and group tickets. If these cuts go through there will be an increase in lonely people especially in rural areas, but also in towns.

Access to a swimming pool, and public transport to attend clinics etc. A local "Good Neighbours scheme to help with shopping, gardening etc.

I want my family and me to feel supported at the end of life a must.

The reassurance from health professionals that my health is at no risk

Assistance with mobility and personal hygiene

Providing more transport for me

The whole workforce issue is the fundamental issue for the NHS and social care systems. We must train sufficient doctors, nurses, physiotherapists and other health professionals to meet the needs of a population which has growing numbers of older people.

The knowledge that I would be able to relocate to suitable assisted housing to allow the various surgery and ongoing management of chronic health issues to be achieved

I believe it is dangerous for older people to stay in their oversized homes and have lots of money spent on alterations and care when they would be better suited in independent living, care home etc. The NHS need to step in, too many times have doctors said its ok for older people to drive - its not, its dangerous. There needs to be a stage where the NHS have to step in and say its time for you to move out, before they fall and break a hip. Even though a community should support in the way of having groups and classes etc in a community hall, they should not take the fall back because an older person is too stubborn to move from their home and too stubborn to stop driving for the safety of those around them. The healthcare professionals need to be realistic and it must be difficult as they only see them for 15 minutes a time, but it is dangerous to let them stay in their homes which are too oversized for what they need and to drive a metal vehicle which can kill - therefore causing the NHS more money when they attend that accident, when they attend a fall which has broken their arm etc etc etc.

Investment in community support

Knowledge about my whole condition, so that conditions aren’t treated in isolation

Funds to be able to adapt my home if needed

More local professional support.

End of Life should be up to the individuals choice

Secure income
Regular health reviews
One to one card at end of life.   Private rooms not wards when receiving palliative care. Access to hospices for example
Good Support /Emotional/ Social and Emotional Support to Carers
good and easy bus routes to local places such as lesiure centres
Carers whether they are helping me in a nursing home/care home or in my own home to be better trained/educated to do a good job, lots of good carers but equally too many who aren't up to the job but agencies struggle to get decent carers as low paid
Peace if I d that support is available if needed
More exercise and activities for aging population.
If I became ill aand in pain and wanted to pass away, I would be supported in my decision
Better information, that is integrated between preventative actions I can take and practical ways I can manage my own health if it deteriorates.
Social groups to be available to elderly people to allow them to mix with other people who have shared interests. Very few social groups available, many elderly people living alone solely focus on what their issues are but being involved in social activities takes their minds off illness and ailments for a period of time and gives them something to look forward to.
Staying at home and being able to support myself
From what I see, you only get support when hit crisis point. Services & support need to kick in sooner than that to enable me to make informed decisions, so not left with everything happening to me with no choice.
Far better financed support services of a high standard not minimum wage, basic training only staff.
Public transport being available long term
Less red tape
Easier accessibility to services, both in terms of having more chances to access those services locally, possibly in local clinics, hubs or GP practices, and also by having transport (not necessarily free) available when too old to drive. Constant reliance on neighbours is counter-productive and means patients will miss appointments, rather than admit they cannot keep depending on the goodwill of others,
A warm home, sufficient income and not feeling lonely.
Enough money to buy the things which support me without having to jump through hoops to not only get it in the first place but to retain the money once the things I use help me rather than someone arbitrarily deciding that because I seem to be doing well that I must therefore not need help anymore to stay that way.

W should not have to rely on family and friends to support us, especially with long term conditions. Having knowledge is one thing. But Being a full time carer (or even part time) as expected now, takes its toll on carers health.

To have appropriate support underpinned by a meaningful plan with an accountable clinician.

Funding of local resources
If the NHS/ social care need£1m but have £500k cut it is no good giving the spin that they are investing £ over the next 5 years which does not cover the Massive gap already . Managers are now accepting budget cuts and given up

Support for my family

To be at home as long as possible

Better community response to home

The importance of support to home carers Social, Emotional and Psychological

A designated person with all the information as to where I live and the facilities I am able to access considering my situation with regards access to transport etc

More understanding and awareness of people with mobility scooters.

Information accessed via eg an App or website to help signpost Carers and the Patient towards how to access support. From my perspective it all seems disjointed and ad hoc.

more support for those caring for and about me

Better access to preventative services in the community.

End of life care has to be improved and seen as important and needs to be funded centrally not reliant on those that can afford it or charities to pick up the care bill e.g. hospices. End of life care is as important as birth and other issue.

Good suport + for people to listen to what I want

Better and more state run care/residential homes

When you are ill and on your own and you don't drive you will need support of some one to get you to appointment in a timely manner without having to pick up loads of other people and spend all day getting there and back

Enough high quality support in the community which is properly funded. The services should be seamless with one point of contact and knowledge shared about my condition.

Honesty about the length of life left, so realistic arrangements can be made for palliative care. Access to pain relief specialists.

Honesty about the length of life left, so realistic arrangements can be made for palliative care. Access to pain relief specialists.

Keeping fit.

Having the support available and not having to wait months for this support

Carer's support. I have a disabled mother and unwell father, yet receive no support and expectations from medical professionals on me are extremely high.

Local access to GP services - within 2 miles. Being able to get GP appointment when needed and not having to ring at 8am to be told all the appointments have gone for the day.

Better health visitor services to carry out minor care, checking dressings and giving injections.

Of course information and choices. However, again what can often make the difference is listening to patients and respecting the elderly rather than dismissing them, which I fear sometimes happens.

Hospital car parks are always full, the stress of parking is terrible, especially to visit someone just admitted or in A&E. There should be nearby land to park at a nominal cost and a direct and frequent transport service to the hospital. Like 'Park & Ride' schemes.

I notice there are few older people using my gym - I personally plan to keep going there as long as I can, keeping my muscles and heart in reasonable condition so I'm hopefully less of a burden on anyone else further down the line (I'm mid-fifties now). I'm lucky to be able to afford this, but perhaps people on a pension are reluctant to spend money on what they may percieve as luxuries like gym membership. Could you lean on the local authorities to offer at least reduced rate if not free access to council leisure facilities/gyms for pensioners? Otherwise, I guess I would say support for some personal care in my home if I make it to seriously old age! Also, oddly, IT literacy for older people. Online shopping can make life a whole lot easier for people who struggle with mobility. It can all be done on a cheap smartphone, but many people don't know how. A small thing I know, but if people don't have access to shopping and can't actually get food and clothes to the house, the temptation would be to look to residential care. Further to this, opportunities for older people to integrate and be involved. Not just with each other, but with the community. Shopping delivered to the door is great, but the mind needs feeding too. I'm asking a lot here and I think some of it is about cultural change too. We're living longer and need to rethink what goes on in those years. The Japanese are starting to talk about "the young old" - the extension of middle age into the sixties and seventies where people are still fit and healthy and able to contribute. As a society we're not really geared up for this yet and these people are still in the retired/scrapheap bracket when in reality this is not the case. The latest statistic I heard on employment figures for this age group was that 1 in 4 people who retire are back in work within 12 months!

I think that all people should be given a choice about end of life care...when they are old enough to understand what it means....I am currently 68 and fingers X reasonably well and happy for my age.

I am in NO doubt though, that if I were at deaths door- I would like the choice to choose when to exit this Planet, so that I wouldnt have to go into an old folks home (aaaaghhhh!!!!) and that suffering is not prolonged , and the choice should be given to the individual by their GP ideally, when they are of sound mind, and put on the patients notes....if this does NOT happen, I personally would like to find an "Exit-pill" so I dont have to go all the way to Switzerland !!

It seems that easier access to a known GP is very important. Or another member of the care profession at my local surgery.

Good communication with the appropriate support organisations, this to include internet communication if possible.

Good communication with the appropriate support organisations, this to include internet communication if possible.

How you interact with your local NHS

The NHS wants to adapt to make it easier for people to access support they need, when they need it.

6a) Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:
I have absolute confidence that my personal data is managed well and kept secure
I can access services using my phone or computer
I can talk to my doctor or other health care professional wherever I am
I can make appointments online and my options are not limited
Any results are communicated to me quickly making best use of technology
I manage my own personal records so that I can receive continuity in care
I am able to talk to other people who are experiencing similar challenges to me to help me feel better

I have absolute confidence that my personal data is managed well and kept secure

	Shropshire	Telford & Wrekin	Grand Total
Not important at all	1		1
Not important	1		1
Neutral	18	12	30
Important	49	24	73
Very important	92	76	168
Blank	6	4	10
Grand Total	**167**	**116**	**283**

I can access services using my phone or computer

	Shropshire	Telford & Wrekin	Grand Total

Not important at all	9	1	10
Not important	3	3	6
Neutral	14	9	23
Important	60	35	95
Very important	76	65	141
Blank	5	3	8
Grand Total	**167**	**116**	**283**

I can access services using my phone or computer

	Shropshire	Telford & Wrekin	Grand Total
Not important at all	9	1	10
Not important	3	3	6
Neutral	14	9	23
Important	60	35	95
Very important	76	65	141
Blank	5	3	8
Grand Total	**167**	**116**	**283**

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

	Shropshire	Telford & Wrekin	Grand Total
Not important	6		6
Neutral	22	9	31
Important	56	37	93
Very important	78	68	146
Blank	4	2	6
Not important at all	1		1
Grand Total	**167**	**116**	**283**

I can make appointments online and my options are not limited

	Shropshire	Telford & Wrekin	Grand Total
Not important	7	2	9
Neutral	22	11	33
Important	53	21	74
Very important	75	79	154
Blank	4	3	7
Not important at all	6		6
Grand Total	**167**	**116**	**283**

Any results are communicated to me quickly making best use of technology			
	Shropshire	Telford & Wrekin	Grand Total
Not important at all	2	1	3
Not important	2	1	3
Neutral	7	6	13
Important	49	28	77
Very important	103	76	179
Blank	4	4	8
Grand Total	**167**	**116**	**283**

I manage my own personal records so that I can receive continuity in care			
	Shropshire	Telford & Wrekin	Grand Total
Not important at all	4		4
Not important	6	4	10
Neutral	36	18	54
Important	53	37	90
Very important	63	55	118
Blank	5	2	7
Grand Total	**167**	**116**	**283**

I am able to talk to other people who are experiencing similar challenges to me to help me feel better			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Not important at all	2	1	3
Not important	17	7	24
Neutral	47	19	66
Important	56	41	97
Very important	41	45	86
Blank	4	3	7
Grand Total	**167**	**116**	**283**

6b) If there was one more thing that you think need to change to help you to successfully manage your health and care, what would it be? [free text]

Summary:

Themes raised in the answers.	Number of responses			
	Shropshire	Telford & Wrekin	Total	Rank
GP Surgeries	10	16	26	1
Better Access	7	11		
Example comments: • “A doctor who has time for me” • “having access to the same Doctor...” • “To be able to see your GP without having to wait a long time”				
Developing Technology	19	6	25	2
Negative comments around IT	8	3		
Example comments: • “A confident and robust online presence using latest technology” “improved digital access”, “Elderly people are not always computer literate…”				
Education & Research for professionals/service users	9	8	17	3
Example comments: • “Professionals should acknowledge patients’ support groups….” • “Correct information” • “understanding of the options available for ongoing treatment….” • “Better educated health service employees”				
Staffing & Service provision	9	5	14	4
Example comments • “increased staffing levels…” • “more doctors and nurses…” • “the way people access services particularly mental health help….”				
Communication	9	2	11	5

Example comments: • “better communication between services and hospital departments” • “I wish to be kept in the loop with updates, particularly when being referred to another service…” • “ full communication of test results”				
Patients Records	4	3	7	6
Example comments: • “On line access to my medical records….” • “All medical records kept on a single data base and available to both patient and medical practitioners….”				
Self Care	1	2	3	7
Example comments: • “moderate exercise” “learning to look after myself”				
Non-specific comment	3	0	3	7
Example comments: • “nothing”, “not sure”				
Support	1	0	1	9
Example comment: • “getting good support for me and my family”				

Comments:

When developing technology for health I think it is important to consider that many people (including young people) are not always as confident at using technology as people think. I want to be shown how to use this technology to make sure I can get the best out of it and be assured that it is something I can access wherever I live. In Shropshire there is a wide variation of wi-fi coverage, access and reliability.

To be able to get a GP appointment instead of speaking to a call centre who promise to call back but rarely do. It’s so frustrating just to try and get an appointment.

Increased staffing levels so I didn't have to wait too long for professional advice or support

Talking to a real person face to face or on the phone is very important to me not just internet communication. I want to know who the professionals are dealing with me not nameless, faceless 'professional strangers' who know everything about me but I know nothing at all of them or the stream of ever changing people passing me from one to another.

For those who struggle with technology due to strokes or other disabilities ensure that the telephone systems work so that patients who need to speak on the telephone can be served.

Improving out of hours coverage

Using technology Tele health don’t have to move around different services and waste time

Stop forcing everything online, I don’t want automated everything, I don’t want scripts sent to a miscellaneous pharmacy

Elderly people are not always computer literate. They would need support/ advice to use new technology

Having access to the same GP. Fed up with having to explain symptoms again and again and GPs not even checking my history before the appointment.

Personalised technology.

I wish to be kept in the loop with updates, particularly when being referred to another service, so that I'm not waiting not knowing what is happening or how far along the process is or is not,

I don't use a smart phone or have a computer. I need to be able to talk to someone on my landline

update all computer systems in the NHS, every trust should work on the same system and this should link up primary and secondary care. bring out one NHS, gov owned system and roll it out across the country. this will also aide any data breech issues and all big data stored on the deep web and not acessible outside of the Gov protocols. Not happy about the Google deepmind project!!! this is not safe and should not hold the nations health data, include genomic info!!

Effective communication

I have found it increasingly difficult to manage low blood sugars as sugar and glucose are being removed from everything. While I understand the need to manage the obesity of the nation, I doubt this measure is having much impact on that, but the impact on people with Type 1 diabetes can be catastrophic.

Those not in work / school (ie retired / unemployed etc) are not given apppointment times before 9am and after 4pm.

The NHS should get rid of all that paper work and communicate as everyone else seems to do nowadays.

Seeing practitioners without having to wait weeks/months.

Good true information about my condition(s)

I have 2 specialists gastroenterology and neurology. I am always copied in to my reports from the later, but never from the first .
Patient access is only good for repeat prescriptions.
Very rarely see the same GP , so feel like a number not a person.

As we are in a stage of transition... the long term goal being interactions being conducted online BUT
Still a majority of population still rely on phone contact
As a society we DO not know the relevant nos anymore for all services
In crisis who do we contact
Which hospital should we go to (eg poss broken leg do we go to community hospital with X Ray facilities or go to A and E)
We need clear and current instructions on where/ how to access help

To use technology more so I do not have to go into the practice if possible

Access to services outside normal working hours

Better communication

I think these comments are for an ideal world and we have to realise that the NHS is enormous. I have been in hospital 2 months ago and I am so impressed with the treatment I received and the kindness from nearly all staff. Having worked in the NHS 40 years ago and the changes I see now it is brilliant. There are always things to be improved but I consider myself so lucky to be in this country and to receive the treatment I receive. I could go on as my little granddaughter was born with a blood clot in her leg and she had the best of treatment from a London Hospital where she was transferred to.

NHS has spent millions on IT eg connecti g health and no project has ever been finished - IT is s vehicle for communication - the value base is patient focused local services easy access and what information is essential are the guiding principles- loads of info in nhs is unnecessary and not used but feeds the machine - making the sysytems clinically focused and not business focused - freeing up clinicians to attend meetings etc as my experience is that staff are withdrawn and the clinical sysyresms becone more bureaucratic and finance/ performance management focused as they have the time to attend meetings - bring in us ex NHS staff to provide advice and support !

All medical records kept on a single data base and available to both patient and medical practitioners. Every patient issued with a barcode/card so that should they be taken to hospital or a paramedic needs to treat them in situ and should they be unconscious more accurate treatment could be administered and time could be saved.

Skype calls with GPs . Hospital records included on my health record - there are no mention on my GP record of issues I have had which have been treated in hospital

I know for certain that clinical staff would like to understand what is available from the voluntary sector so they can support patients more effectively in Shropshire. There is a lack of knowledge and understanding of staff of the voluntary sector pathways and signposting.

What a shame the countrywide computer system was ditched.

These questions above are the utopia. Unfortunately the reality is different. The NHS should have its own network not be on the public network. Share the data with between each other and also the local surgeries. Fax is old tech and slow and unreliable. Email email email. My doctor should be able to email me and I should be able to email him. Letters are too slow. Embrace the tech!!

Being able to get a doctors appoint is hopeless

Better communication between services & hospital departments

Online access to my medical notes held by my GP, hospitals and other health service providers.

The way people access services particularly mental health help, before crisis point.

A manual would be very helpful not for the patience.

Appointments available online and on telephoning doctors, being given your own copy of all records as sometimes important paperwork is lost in the system.

Realisation that not everyone has the internet

Nothing

Technology should be better used so that you can see what wait times are anticipated. All Hospitals should monitored weekly/monthly to be clear and answerable on wait times

A confident and robust online presence using latest technology and Apps

To be able to see your GP without having to wait a long time

Better personal support and teaching at younger ages to look after yourself. Less marketing on less healthy alternatives and more on healthy.

Moderate exercise

Better/more GP appointments. Quicker access to GPs

Have the doctors turn round medication quicker than 3 days

Video conferences would help to decide if I need to actually visit a doctor or whether advice can be offered in other ways.
Nothing should replace the option of talking face to face
To make all the above important aspects a reality. I do NOT believe my records are confidential. I do NOT receive results of tests etc promptly unless I fuss about it. My medical practice does not use e-mail, so I have to go to the surgery for consultations, which I avoid as much as possible, and go to the pharmacy (closer) instead. I do NOT manage my own records. My appointment options ARE limited to staff availability. They DO use the telephone, which means having to wait for ages for their convenience, as patients with surgery appointments have precedence over telephone enquiries.
Opportunity to access human resources to educate.
Opportunity to access human resources to educate.
Learning to look after myself
Health progress tracker of some sort. Able to track the progress/improvement in my health. Idea for a possible app or something.
More nurses/doctors. More equipment in renal units
Experienced support workers
Understanding of the options available for ongoing treatment of my health needs r
Access to appointments
Being able to get through to the doctors surgery when needed and to be able to see a doctor the same day when not well.
Professionals should acknowledge patients’ support groups, they are an enormous help.
I do not have confidence that my data is managed confidentially and securely.
Full communication of test results.
Accessible appointments with GP
GP appointments available
Adequate staffing of local services
Options to speak to professionals when needed not just when suits the medical professionals
Access to Doctors Important . Problems encountered include lengthy Wait fot Telephone appointments with Doctor.
Correct information
To have more access to own medical records.
Doctors appointment system at Wellington Medical Practice....its DREADFUL!
As above. Quality of information that is guaranteed free of 'fake news'!

Electronic patient files that can be shared amongst various health services that the patient uses would be effective. This would free up healthcare workers time as they would not have to spend more time completing paperwork rather than doing what they are trained to do.... care.

A doctor who has time for me!!!

That all health care agencies can access my information and notes. The fact that this is not able to happen in this day and age is a disgrace.
The public absolutely need to be educated in order to take self responsibility for their health issues and care.

Better educated health service employees

Quicker access to health professionals

Seeing decisions made and acted upon immediately would be helpful - e.g. plans are all very well, but not helpful whilst they still remain in the distance.

More research into the physical causes of my condition (which is ME/CFS) and the results of that being communicated to the health profession as a whole but especially GPs

That services are improved in primary care.

Less reliance on IT ! People have this delusion that computers are the ultimate- if systems aren't right before you load up the info then your IT churns out rubbish! We need to focus on the baseline info first and then look at how we communicate it - IT companies and computer geeks make millions but every time we change systems there is a massive learning curve for admin and clinical staff - find the root of the problem (existing ineffective services / information processes/ impact of cuts on teams) and then decide if a new system is required

Improved digital access

Feel less guilty about accessing healthcare

Being able to get into the doctors the same day.

In spite of the complexities in providing a joined up coherent Health Service, that should be a major goal.

No over-reliance on mobile phones and similar technology. Personally I have no reliable mobile signal where I live. I am also aware that many people cannot or will not have access to or use this technology. Some questions posed contain more than one element so difficault to give most apt answer.

I need to be able to access appropriate services when I am actually ill, not wait for 3 weeks until the next appointment. Services need to be as close to home as possible.

consistency of staff, give staff time to read your notes so that you don't have to go over the same thing time and time again. If there is a summary that is incorrect please correct it.....that's how mistakes are made.

not sure

Longer opening hours at GP surgeries

That all relevant information is explained to me in a timely manner

My records are mine but also accessible to other health professionals in the country if necessary.

Access to a doctor by appointment without waiting weeks.
To be able to access the same doctor who knows the problem

As previously mentioned ... An online diary system where I could record significant health events.

As previously mentioned ... An online diary system where I could record significant health events.

Getting good support for me and my family.

Not sure but would like (expect) you to sort as you know best.

More appointments available to speak to doctors outside work hours of 9am - 5pm, not just one night a week.
Stop surgeries closing for one period a week, my mothers surgery is closed on Friday afternoons !!!!!!!
I do NOT want to speak to a receptionist who will decide if the doctor will call me back later and then decide if I need an appointment - this happens in Lawley and is ridiculous.

The ability to make routine appointments in a more timely manner.

To be able to make speedy telephone contact with surgery's and have appointments that are also expeditious. Ringing for hours and then not getting an appointment for weeks is NOT a service.

Don't forget that not all elderly people, patients who are very ill or dementia sufferers can access I T, they need people there who can communicate and reach out to them. They need to feel the warmth of another human being. Don't put everything down to technology!!!!

that different services communicate to each other, if you are transferring to a new service, you usually find that you have to explain everything again over and over to each new service, if there was a way of all services knowing you wouldn't have to keep explaining.

There's so little I would change about the NHS. I would just like to see you NOT being hived off and I would like to wave a wand and grant you unlimited funding. I would gladly pay more tax to see this happen. Gladly. However, if i was looking for a change that would help me, it's actually a quite small one. Any health-related journey tends to start with a trip to see your GP. I work full time, as do my wife and daughter. As do the majority of the working population presumably, yet appointment times were traditionally weekdays within working hours when we're least able to access them! So I guess a bit of flexibility there to make GP appointments more accessible. I'm sure the use of web based interactions will help. On the thankfully few times in my life when I've needed to see a Doctor, only once or twice did they actually need to get "hands on" with me!! It was mainly a questioning diagnostic process which could equally well be done via Skype. Good opportunity for GPs who want to work part-time/flexibly and could do this from a home office.

I do think that Convalescent Homes should be re-invented-so we dont have the bed blocking situation,so people who need time to "Recover" can do so in a professionally run Place, as used to be, thus freeing up Hospital beds, which seems to be an URGENT requirement...and I dont agree with "Home-care"....as many people are too poorly and frail and sometimes live alone....so a proper NHS run Convalescent Home, would freeup beds , and ensure that patents recieve 24/7 of the professional care by the NHS- not be sent home and then be at the "Mercy" of often- undertrained and casual "Carers.

Home care should be available.

Continuity of communication.

Knowledge re how all the above may be achieved.

Knowledge re how all the above may be achieved.
Right, the main problem is NOT being able to contact the doctors. We are often left on hold for a long time. The average time I am on hold for is around 15 mins. On a PAYG phone this costs me a fortune to call the doctor. Plus the other major problem is that appointments are even harder to get.

Tell us what is most important

Out of the statements below, we want you to pick the one that you feel is most important to you.

7. What is most important to you to help you live a healthy life? [pick one]

What is most important to you to help you live a healthy life?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Easy access to the information I need to help me make decisions about my health and care	20	17	37
The knowledge to help me do what I can to prevent ill health	15	13	28
Access to the help and treatment I need when I want it	88	50	138
Professionals that listen to me when I speak to them about my concerns	33	26	59
For every interaction with health and care services to count; my time is valued	6	6	12
Blank	5	4	9
Grand Total	**167**	**116**	**283**

8. What's most important to you to be able to manage and choose the support you need? [pick one]

What's most important to you to be able to manage and choose the support you need?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
If I have a long term condition I decide how the NHS spends money on me	13	7	20
Choosing the right treatment is a joint decision between me and the relevant health and care professional	77	61	138
I make the decision about where I will go to receive health and care support	10	7	17
I should be offered care and support in other areas if my local area can't see me in a timely way	19	12	31
I make the decision about when I will receive health and care support	5	8	13

My opinion on what is best for me, counts	9	5	14
Communications are timely	10	5	15
I have time to consider my options and make the choices that are right for me	17	7	24
Blank	7	4	11
Grand Total	**167**	**116**	**283**

10. What's most important to you to help you keep your independence and stay healthy as you get older? [pick one]

What's most important to you to help you keep your independence and stay healthy as you get older?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
I want my family and friends to have the knowledge to help and support me when needed	15	10	25
I want my community to be able to support me to live my life the way I want	15	13	28
I want my family and me to feel supported at the end of life	26	8	34
I want there to be convenient ways for me to travel to health and care services when I need to	13	8	21
I want to be able to stay in my own home for as long as it is safe to do so	87	72	159
Blank	11	5	16
Grand Total	**167**	**116**	**283**

11. What is most important to you when interacting with the NHS [pick one]

What is most important to you when interacting with the NHS			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Any results are communicated to me quickly making best use of technology	25	12	37
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	2	4	6
I can access services using my phone or computer	18	5	23
I can make appointments online and my options are not limited	12	20	32

I can talk to my doctor or other health care professional wherever I am	69	39	108
I have absolute confidence that my personal data is managed well and kept secure	20	18	38
I manage my own personal records so that I can receive continuity in care	11	10	21
Blank	10	8	18
Grand Total	**167**	**116**	**283**

12. If you have any further comments please write them below. [free text]

I just feel like there is a hind agenda behind these questions which will lead to service reduction or less specialist help being available.
Confidence in the NHS IT systems will need to be improved as it currently is very patchy with some providers using dated systems.
I'm fed up of making so many journeys to see a doctor when I would prefer to be seen at a one stop shop. This would enable me to care better for myself enabling me to get on with living a long healthier life.
This question is framed in terms of what's important to the NHS, rather than to patients. Having access to the same GP and GPs having time to investigate my health issues are most important to me, but they're not on the list.
It matters to me to have and maintain control over lifestyle and treatment options, and to have health and social care professionals take my views seriously. However, there are people who do not have the confidence to make their own decisions and judgements and who would rather the professionals took control. It is important that health and social care professionals are able and willing to adapt their approach to the individual.
I think people should be given far more basic knowledge about how to live a healthy life - eg nutrition, exercise, what to do when they get a mild illness such as coughs & colds, dental hygiene, personal hygiene, good practices for sexual health and mental health. Having worked briefly for an NHS outreach team I was staggered by the general ignorance of basic self-care among our population. A more preventative approach incorporating the above would surely be beneficial for the NHS in the long term?
I would like the NHS professionals to have more staff and time to support patients to receive their need not wants in a timely way. I definitely would like to see the secretary of Health work on one of our hospitals for a week to see how hard they work and how professional they are, and to feel valued and listened to.
I believe the NHS is there for everyone who needs it but looking at the above statements it is not up to people in the community to dictate how they receive their care etc. Things cannot be done as and when people want it. Money is an important priority and it needs to be spent wisely. There are things that can still be done to improve things I am sure and they are being done to save money. I saw staff wandering around having a chat when I went for my pre-op and I had to wait ages to see the staff nurse after all the relevant tests had been done. I could be wrong in my thinking but I felt that they had not got enough to do. When I was back on the ward the nurse was rushed off her feet giving very personal and individual support and care to patients who were upset and very ill and including their families. I was very impressed.

I want to be able to access help and advice whenever and whatever media. I feel treatment is advised, then options are discussed.

Communication is the one single thing that can wreck the efficiency of any organisation, no matter what it's size!! Learning from mistakes is important. Respect of a persons individuality is paramount, whether staff or patient.

It would be wonderful to be able to get a doctors apointment when needed

I feel that staying at home alone with only carers coming in is not a happy way to live. Everybody is talking about how important human contact is, and that loneliness is bad for people, yet we are encouraged to stay at home as long as possible in circumstances like this, to cut costs of care in a home or hospital. We need more retirement homes to cater for old lonely people. This would free up hospital beds and houses for families. Care in the community is a sticking plaster. Many people are afraid to go into a home because of the stories they hear. If homes were funded properly and had good, kind staff people would be happy to be there. Loneliness is frightening and worrying.

I want to be in control of my health and where I can go to receive it in the quickest time

It is hard to choose only one, as so many are equally important.

Within the pressure on the NHS it has become apparent medical professionals are (word unreadable). The patients are just numbers, it is a very sad time. I have gone private just to feel valued.

My personal opinion, we are all very lucky to have such a wonderful free service

All the points on Interacting with NHS are very important, difficult to choose only one

Too many health services are only available during office hours.

It is important that we are listened too, our voices should count. We need to feel more like humans and less like numbers.

Nil

Every question in this survey is a 'leading' question. It does not suggest that the survey was piloted very well!

'Access help and treatment when I want it' doesn't really cover the very great difficulty experienced in simply trying to get a GP appointment without spending hours on the telephone every day. People are likely to put off seeing the doctor in spite of worrying symptoms. I also feel that I'm not welcome to visit the GP to discuss concerns, that I should only go if I'm really ill.

Swift appointments... Not three week waits

Whilst selecting only one option allowed all the points above are equally important including all agencies being able to access my data

Understanding the availability of services and resources locally, that will inspire confidence that what can be afforded is available, and what cannot be afforded locally will still be available somewhere else if needed.

Reduction in negative media coverage of local issues, which causes a lot of unnecessary worry and concern, especially for elderly or vulnerable people.

1) I think it is imperative that the NHS remains a national institution and isn't privatised so that patients do not become cash cows for profit rather than people who need help and support.
2) I also think it is vital that all the health areas talk to each other and work in harmony to cut

down on waste and on conflicting advice. 3) For my own case that research into the causes and treatment for ME/CFS is better supported and there is more help given to patients to deal with the condition. I was lucky to have the services of the Shropshire Enablement Team or I wouldn't be able to use the computer as I am at the moment (among many other things) but that service has now been cut. 4) Also it is important to remember that depression in many cases is caused by having the illness or condition and/or the changes in circumstance rather than being the root cause of the illness or condition in the first place. All illnesses are psychosomatic at some level and to brand conditions which are not yet fully understood by the medical profession as "all in your head" is lazy and dismissive. I am fortunate that those I came into contact with when I was first ill had some understanding of this difficult condition and I was treated well, but many others of my acquaintance were not so fortunate. 5) In terms of growing older I think it is very important not to dismiss people's concerns as "just part of the ageing process" and it has to be put up with. 6) I think it is also very important that GPs have more time to deal with and properly talk with their patients as it is often difficult to get to the root of what is actually bothering someone rather than what they may first present themselves as wanting. In this way I think it is a good idea to have a tie up with all the agencies which can help people rather than just prescribing pills which is largely only good for the pharmaceutical companies rather than for the patient or the NHS. 7) That screening procedures for cancers and such should not have age cut off dates as many of the people I have known who have had breast cancer, for instance, have been older than the cut off date.
The move towards dependancy on AI and technology is a disaster for the most vulnerable i.e. the elderly, people with learning disabilities; people with mental health support needs; Children and babies. The people who will benefitr are the walking well and privaye tech companies again.
The IT theme runs throughout I want to see a doctor when I need not a telephone service Our coagulant service is a blood test and then postal dosing service - no emotional support Switchboards are swamped and Oakengates Take days to get through because it's the wrong nber - - should be 0300 not 01952 The NHS and proper clinical practice is based on human relationships if a proper assessment is to be made.
I want to ensure I have adequate mental health support delivered by suitably qualifies & experienced staff
We need to be more connected and community focussed
Massive need to involve in support/home crises to offer better quality of life for carers
Tailoring of the support and services to my needs, which can be complex as illnesses can come at the same time or add on to one another
One of the key ways to help me stay healthy is by ensuring that I have easy access to free preventative and low-level services in my community. Investment in the NHS needs to be targeted at preventative services, rehabilitation services and public health - sadly, these are the first services to be cut as soon as there is a funding crisis.
No
Being able to talk to the right people at the right time to get the right advice, treatment and support
Services are still fragmented, there is a disconnection between the various medical establishments and people are 'chunked' into the particular ailment that afflicts them rather than the NHS treating

the whole person. Clinics concentrate on the bit of body presented to them without taking into account a long-term condition which may be impacting on the whole thereby causing numerous visits unnecessarily.
I found selecting just one item from the lists pointless ... much like comparing apples and oranges.
I found selecting just one item from the lists pointless ... much like comparing apples and oranges.
All the technology in places is fabulous, especially for the people who work and don't find it easy to get to the doctors surgery's, however it is impossible to get a appointment when needed along with when you do get one, they don't listen to your concerns and have you back out within 5 minutes, this just makes the situation worse even resulting in admissions into hospital
See above comments
Make the NHS a level playing field - not a Welsh, Scottish, English, N.I. but a National Health Service. Living in Shropshire (on the Welsh border) I hear that the English NHS have problems getting payment for treating those living in Wales and that Welsh hospitals / consultants have refused treating English living patients.
Again none of the above comments mentions being able to speak to someone in person or see that person in the flesh. Its NOT all about technology.
It was hard to choose what is most important to help me live a healthy life! I have said access to help and treatment when I need it because I already look for good sources of information on healthy lifestyles and manage my own health well, so although I feel others would benefit from that information, I'm able to find it for myself! So the support I need is when things go wrong that I can't manage for myself!!

Tell us a bit about you

By telling us more information about yourself, you will help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

13. Your age

Your age			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Under 18	1	2	3
18-24	7	4	11
25-34	10	10	20
35-44	9	12	21
45-54	34	35	69
55-64	52	16	68
65-74	39	22	61
75+	15	14	29

Blank		1	1
Grand Total	167	116	283

14. Your ethnicity

Your ethnicity			
	Shropshire	Telford & Wrekin	Grand Total
African		1	1
Any other mixed background	1	1	2
Any other white background	3	5	8
Arab	1		1
Asian British		1	1
Black British		2	2
Gypsy or Irish Traveller	1		1
Other	2	1	3
White British	153	100	253
Indian		1	1
Blank	6	4	10
Grand Total	167	116	283

15. Do you consider yourself to have a disability?

Do you consider yourself to have a disability?			
	Shropshire	Telford & Wrekin	Grand Total
I'd prefer not to say	7	3	10
No	112	82	194
Yes	47	30	77
Blank	1	1	2
Grand Total	167	116	283

16. Are you a carer?

Are you a carer?			
	Shropshire	Telford & Wrekin	Grand Total
No	138	84	222
Yes	27	26	53
Blank	2	6	8
Grand Total	167	116	283

17. Do you have a long term health condition?

Do you have a long term health condition:			
	Shropshire	Telford & Wrekin	Grand Total
No	77	53	130
Yes I have a long term health condition	52	35	87
Yes I have more than one long term health condition	37	20	57
Blank	1	8	9
Grand Total	167	116	283

18. Which of the following best describes you?

Which of the following best describes you?			
	Shropshire	Telford & Wrekin	Grand Total
Asexual	1		1
Bisexual	1		1
Gay or lesbian	3	4	7
Heterosexual	139	105	244
I'd prefer not to say	15	2	17
Other	6	2	8
Blank	2	3	5
Grand Total	167	116	283

19. Your gender

What gender do you identify as?			
	Shropshire	Telford & Wrekin	Grand Total
Female	114	66	180
I'd prefer not to say	2	1	3
Male	47	48	95
Other	1		1
Blank	3	1	4
Grand Total	167	116	283

20. Your religion

Your religion			
	Shropshire	Telford & Wrekin	Grand Total
Christian	83	70	153
I'd prefer not to say	10	4	14
Muslim	1		1
No religion	60	40	100
Other	11	1	12
Blank	1		1
Buddhist	1		1
Hindu		1	1
Grand Total	167	116	283

Appendix 2: Questionnaire 2 - NHS support for specific conditions

1. *Do you consent to Healthwatch using your responses?*

- Yes (If yes, go to Q2): 165
- No (If no, go to Q27): 0

2. *Pick the area that best describes where you live*

- Shropshire: 77
- Telford & Wrekin: 88

3. *Please select the condition you would like to tell us about*

Please select the condition you would like to tell us about			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Autism	3	8	11
Cancer	8	9	17
Dementia	4	5	9
Heart and lung diseases	4	7	11
Learning disability	10	9	19
Long-term condition e.g. diabetes, arthritis	29	33	62
Mental health	19	17	36
Grand Total	**77**	**88**	**165**

4. *Who are you responding on behalf of?*

- Myself: 107
- Someone else: 58

5. *Has the condition you are telling us about started within the last three years?*

- Yes: 60
- No: 105

Your experience of getting help and support

6a. When you first tried to access help, did the support you received meet your needs?

When you first tried to access help, did the support you received meet your needs?			
	Shropshire	**Telford & Wrekin**	**Grand Total**

No	28	27	55
Somewhat	22	33	55
Yes	23	26	49
Not applicable	3		3
Blank	1	2	3
Grand Total	**77**	**88**	**165**

6b Tell us whether the support met your needs and how it could have been improved [free text]

Summaries:

Themes from the questionnaire with examples: **Dementia**	Respondents
Support for carers	2
• Lack of Resources to meet the needs of Carers.	
Information & Advice	2
• "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"	

Themes with examples: **Learning disabilities**	Respondents
Communication with patient	4
• "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 & Advice	4
• "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"	

Themes with examples: **Autism**	Respondents
Information & Advice	4
• "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 services	3
• "Felt like I was passed around from person to person"	
• "I had many appointments before being given support. I saw so many different people"	

Themes with examples: **Long-term conditions**	Respondents
Listen to me	13
• “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”	
• “GP not interested in listening to my concerns or possible other options”	
Access to specialist services	11
• “Provide more specialists in Shropshire for specialist conditions.”	
• “Replace the missing Parkinson’s nurse”	
• “Good, caring and helpful support from specialist nurse/technician.”	
• “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”	
Communication with patient	10
• “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”	
• “Discovered by accident that service location and support model had changed”	
Continuity of staff	9
• “AT current GP surgery. Constant Locum GPs, can’t seem to keep staff.”	
• “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”	
Information & Advice	7
• “Education on long term conditions and impact on families.”	
• “Information on support services / groups would have been useful.”	
• “I was not told what to expect with on-going condition.”	
Communication between staff/services	6
• “There was poor communication between the person doing the tests and the doctor”	
• “Anytime I tried to see a doctor I’m having to constantly repeat myself…. Communicate with each other”	
Condition review/monitoring	6
• “Timely checks on long term conditions”	
• “Undertake regular check-up / scans to monitor changes and provide me with accurate current picture to help me decide how to manage my condition”	

Themes with examples: **Mental health**	Respondents
Access to specialist services	5
• “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"	
Information & Advice	4
• "Clear information and advice that goes into the right amount of detail for the individual."	
• "better information and drop in points"	
Communication with patient	3
• "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	3
• "See the same practitioner who is familiar with my progress."	
Access to services outside 'office hours'	3
• "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	3
• "A lot of mixed communications between professionals."	
Condition review/monitoring	3
• "Regular three or four months check-up just to make sure all is well, so not to relapse."	
Support In the community	3
• "GPs need to refer people to the available support groups can offer in the community."	

Themes with examples: **Cancer**	Respondents
Access to specialist services	4
• "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 & Advice	2
• "Advice and guidance, reliable information in different formats" [would help me stay healthy and manage my condition]	
GP access	2
• "Make access to GP easier & be able to see the same GP."	

Themes with examples: **Heart and lung disease**	Respondents
Communication with patient	3
• Shrewsbury [SaTH] communication non-existent	

All comments:

Autism	Initially no recognition of problem then a long wait for diagnosis with poor follow up support.
Autism	Got no support at first until finally got a referral to CAMHS
Autism	Professional need to be more aware of condition to enable them to understand condition and how it impacts on both the person diagnosed and their families and carers.
Autism	Mental health services for children was poor then and is still poor. Not enough doctors, long waiting lists, feeling very forced in to agreeing inadequate treatments so child can be discharged.
Autism	Took a long time to be listened too, not a lot of support.
Autism	I had many appointments before being given support. I saw so many different people
Autism	We have had a lot of support with her Autism diagnosis. As a parent we knew she had additional needs from an early age. She showed signs from the age of 2 onwards. We spoke to our healthvisitor about it and she gave us lots of information and places to reach out too. The nursery had also been very supportive in getting additional help from 3 years old. She has now been diagnosed at the age of 5 after many assessments.
Autism	Support was provided but after diagnosis i struggled to find support and know who to speak too.
Autism	Health visitor was great and MDA started up quite quickly. The experts were wonderful, explained things well.
Cancer	The support at the hospital was ok but as soon as I was discharged there was little or no support offered. I have found out about community groups myself as the hospital did little to promote community voluntary groups
Cancer	At the time was completely overwhelmed by the professional jargon didn't really understand the treatment i was given (still have no idea of chemo names , long term effect etc.
Cancer	My sister had HER2 breast cancer tumours on her spine and brain. She also while undergoing chemotherapy suffered a stroke.(birmingham). She had no support from her gp, the Macmillan nurses visited once, when I requested some help the gp sent the district nurse who in her capacity was not able to help and did not understand why they had sent her. I rang the practice and Macmillan nurses to no affect. She was in a dreadful state towards the end and died in the queen Elizabeth hospital. I was disgusted at the lack of support received.
Cancer	Faster response initially.
Cancer	long wait for initial tests
Cancer	she had her first round of treatment for cancer in her bone marrow and she seemed to be doing really well but then she started getting really bad back pain and doctors wouldn’t listen to her

Cancer	Doctor and nurse very good as mother had dementia as well. So took time to explain and often repeated themselves without hesitation. Also after diagnosis nurse took time and gave family information. The only thing that could have been improved was the time of the appointment to when we actually went in. Good support afterwards through consultant Oncologist and Radiotherapy.
Cancer	Gynecologist is excellent only trouble is I have to travel to stoke to my appointments and finding a car parking space is terrible and expensive I had my lymph nodes removed in my groin the pain I get sitting in a car from telford to stoke is awful if I did have operation at stoke but closer hospitals with gynecologist should be able to see me through recovery instead off having to travel so far when having problems with my wound.
Cancer	Initial diagnosis was not provided carefully enough.
Cancer	conditions for support changed over a period 201-2018 as diabetes, arthiritis, dementia, and eventually cancer became evident.
Cancer	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! !
Cancer	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! !
Cancer	The support was excellent
Dementia	Carers Support limited . Did not allow breaks away from 24 hour Caring More Positive Support needed for Carers to prevent Breakdowns in Support and Expensive and inappropriate Hospital admissions
Dementia	Took ages to get referred to memory clinic for diagnosis.
Dementia	Faster response from diagnosis to getting help is needed
Dementia	Found memory service good but it went to quick and did not feel we had time to take it all in
Dementia	We had support from the memory clinic and doctor.
Dementia	Not enough information about care available to Alzheimers patients when they are unable to live alone any longer.
Dementia	Not enough information about care available to Alzheimers patients when they are unable to live alone any longer.
Heart and lung diseases	Earlier diagnosis
Heart and lung diseases	i think that doctors are so busy that they don't have the time to fully investigate properly. I had an appointment for physio for arthritis but was a closed case as soon as i had been once. No follow up at all.
Heart and lung diseases	There was a 2 month delay in my having cardiac surgery (stents), I recieved no explaination as to why there was a delay. Also I had no cardiac support, my GP couldn't help. After the surgery a cardiac nursing sister forced me to take 'blood pressure reduction' medication which wasn't needed, made me very ill and the

	consultant immediately stopped me taking. All through the 5 months period, from heart attack to surgery, I felt totally isolated and neglected. Now almost 3 years on I still feel isolated and neglected and I have no future appointments or assessments relating to my non-operational condition.
Heart and lung diseases	It took a long time for the condition to be diagnosed
Heart and lung diseases	Received help from GP & Private medical care
Heart and lung diseases	This relates to my first referral by GP in 1998 to local hospital. After trying to manage my issues was then correctly referred by a registrar 2002, to specialist centre for ongoing care. Better understanding at GP level at specialist services , particularly if out of area,
Heart and lung diseases	I can't always get an appointment to see my GP
Heart and lung diseases	Local diagnosis failed, referral to Stoke identified Aortic dissection missed at Shrewsbury!
Heart and lung diseases	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.
Learning disability	Okay, I have support (family)
Learning disability	The support was ok, I got support from the staff to go to the doctor
Learning disability	IT TAKES A LONG TIME TO SEE THE PROFESSIONALS
Learning disability	It would of been a lot easier if it was quick instead of having along wait on the waiting list and I'm still waiting for the report back which was over two months ago
Learning disability	Quicker response for referral and more advice and support
Learning disability	The entire experience could of been so much better. Wasn't referred for a long time. Paediatricians called us liars.
Learning disability	Long process
Learning disability	Doctors were good
Learning disability	My doctor is very good so I don't know
Learning disability	Lots of pathways given to get support
Learning disability	Support worker was involved
Learning disability	Quite happy
Learning disability	All needs were met
Long-term condition e.g. diabetes, arthritis	For mental health I was aware I needed to rule out autism for the route of my stress. The referral went to a therapies hub as that was the only option for my GP. We both knew that there was nobody to test for autism or learniing difficulties in adults. This lead to an inapropriate conversation with a psychiatric

	nurse who was triaging. Her lack of autism awareness reares its head and she behaved in a very offensive way. It didnt meet my needs...it left me veryy angry and offended. A straivght referral straight through to an outside phychiatrist would have been more appropriate. If it is known that there adults out there with undiagnosed autism surely putting some money in a fund ready would help and GPS told to go straight to the specialist. Or better still employ someone in Shropshire who is specialised in this way. Using an indicator test sooner rather than later would have helped. Attitudes were awful. I understand that there is a lack of knowledge and training for mental health in autism.
Long-term condition e.g. diabetes, arthritis	My husband was diagnosed with a fatty liver but was not given the dietary advice that actually both reversed his fatty liver and cured his gout so that he was able to stop taking alopurinol, a drug he was told he would have to take for life. Following a low carbohydrate, higher healthy fat and moderate protein diet as advocated by Dr Aseem Malhotra has allowed him to easily lose 2.5 stone, reverse his fatty liver and cure his gout. When we explained this we were not supported and there was no interest that might help other patients.
Long-term condition e.g. diabetes, arthritis	More support for people with Parkinson`s. More consultants and another nurse.
Long-term condition e.g. diabetes, arthritis	My condition ME/CFS has not had sufficient effective research to give the medical profession much guidance on how to deal with it, especially as for years such research was hi-jacked by a coterie of psychiatrists who tried to dismiss the physical causes of the disease. Flawed research also has provided some inadequate and often harmful advice which has meant that the medical profession has mishandled the condition. I was fortunate to have a GP who acknowledged that she knew little about it and so did everything in her power to help me and who listened to what I managed to find out and acted appropriately. Since her retirement, however, I haven't found anyone who seems to have quite the same understanding and willingness to try things out.
Long-term condition e.g. diabetes, arthritis	Communication poor between medical professionals , access to appointment's.
Long-term condition e.g. diabetes, arthritis	It varies
Long-term condition e.g. diabetes, arthritis	The support received for diabetes care in Telford and Wrekin is sorely lacking in terms of patient education and prevention of complications.
Long-term condition e.g. diabetes, arthritis	Support was great and offered help within the renal unit
Long-term condition e.g. diabetes, arthritis	The support was just what was required. At that time there wasn't any need for improvement. It met a wide and diverse group of vulnerable people.
Long-term condition e.g. diabetes, arthritis	This was in 1996 when ME was recognised as a biomedical illness, and I got good support. Got better enough to look after myself but not to work. After 2005 it changed. The name changed. Now Chronic Fatigue Syndrome. Support become GET and Graded Exercise. this has made some people very ill as the illness has

	not been understood. This is still the same. Not only could there be more support, but more research (there is quite a lot abroad, but we spend very little on biomedical research) specialist doctors and nurses etc. I see a private GP as can afford it, and got back to part time work, but help from NHS is sadly lacking.
Long-term condition e.g. diabetes, arthritis	As my main condition is multi-skeletel being treated and also have preventative treatment so that I can be independent and good pain relief
Long-term condition e.g. diabetes, arthritis	as learnt more info of my condition high blood & cholesterol, & wanted to discuss different options, GP not interested in listening to my concerns or possible other options
Long-term condition e.g. diabetes, arthritis	After having the condition for 30 years my Gp referred me to the nurse led arthritis clinic which was so basic it was not helpful
Long-term condition e.g. diabetes, arthritis	I was only offered the discredited graded exercise therapy for my myalgic encephalomyelitis despite the evidence that it is damaging. I have been recommended this by all the health professionals and though I initially tried it it made me worse. The rhumetologist I saw didn't listen and talked over me.
Long-term condition e.g. diabetes, arthritis	Waiting time for clinics need to be improved - Scans at Oswestry have a 12 to 14 week waiting list - unaccelptable. Clinic reports to GP not acted on in a timely manner.
Long-term condition e.g. diabetes, arthritis	My 92 year old aunt has had chronic venous leg ulcers for approximately 5 years and is of the generation who won't make a complaint. The single handed GP practice in Madeley provided an extremely poor service, insisting that she managed the slough herself and walked to the practice (using a zimmer) without dressings in order for them to be dressed by the practice nurse. There have been several changes of practice nurse and unqualified nurses over this time with no consistency in treatment. She was not put on any wound management pathway until, finally, she was recently referred to a tissue viability clinic and is slowly making progress. Her quality of life deteriorated during this time. If tissue viability expertise could be provided in primary care, through supervision and occasional specialist clinics with clear evidence based SOPs for treating such ulcers she (and others like her) could be spared years of pain and misery
Long-term condition e.g. diabetes, arthritis	I have Multiple Sclrosis (MS) and Rheumatoid Arthritis (RA). Since diagnosis of MS in 1999 and RA in 2008, I have had good care and treatment, but social support has not been quite so good. We have adapted our house/bungalow at our cost, which we found very difficult especially as I had to give up work and cope with a massive reduction of money coming into the house as I am now on a I'll health pension. PIP definitely helps, but I cannot get employment and support allowance as my pension is just above the cut off for receiving the allowance.
Long-term condition e.g. diabetes, arthritis	I paid private in the end
Long-term condition e.g. diabetes, arthritis	Whilst pregnant I started having pains in my lower back, the GP advised me it was normal due to the body changing. I was advised to take paracetamol and place a hot water bottle on the area when the plane increased. After pregnancy it still continued, and has done to this day. I have finally been

	told it is sciatica and referred for physio therapy but I do feel as though I was not listened too especially by my GP.
Long-term condition e.g. diabetes, arthritis	The condition is Ataxia. It's very rare , only 10k cases in UK. Many GPs know nothing about it or the two specialist centres in the UK that can help
Long-term condition e.g. diabetes, arthritis	Stop putting EVERYTHING down to depression. Gp could and should have paid more attention to what I was saying and referred me for help rather than pushing pills down me.
Long-term condition e.g. diabetes, arthritis	It took 18 months to diagnose ME. I had to pay privately for that. An eight week course was offered but people running did not realise how difficult it is for people with ME to attend a course. It takes up so many energy.
Long-term condition e.g. diabetes, arthritis	Actually being listened to. having questioned answered
Long-term condition e.g. diabetes, arthritis	No they failed due to judging and not correctly meeting needs or checking or chasing medical records was treated like I was making illness up
Long-term condition e.g. diabetes, arthritis	Better communication could have been present. I was not told what to expect with on going condition.
Long-term condition e.g. diabetes, arthritis	We were originally told there was mental health support for our daughter (has diabetes), ourselves and our son. When we asked for help, as our son now has severe anxiety since his sisters diagnosis we were told that yes we could all be referred for family Counselling but unfortunately this would not happen due to lack of funds.
Long-term condition e.g. diabetes, arthritis	There was a significant delay (8 months) between the GP referral and the individual actually being seen at the Ophthalmology Department. The quality of care provided by Ophthalmology is good but there are still delays in receiving ongoing treatments (injections).
Long-term condition e.g. diabetes, arthritis	The initial response was very good. But there was no follow up.
Long-term condition e.g. diabetes, arthritis	Initially my GP put me off but thankfully another GP in the practice recognised the symptoms and after a blood test I was diagnosed with the condition and was then referred to the correct department within the local hospital
Long-term condition e.g. diabetes, arthritis	Wider variety of activities to be offered
Long-term condition e.g. diabetes, arthritis	Felt like no one believed me
Long-term condition e.g. diabetes, arthritis	It could have been improved by more communication, not having to chase for answers and diagnosis. Going through 4 different doctors was pretty frustrating.

Long-term condition e.g. diabetes, arthritis	Advice and education was well done. I am aware that the personnel in the department that did this is half what it was at that time. Access to ongoing support and practical help is now reduced to one site and a few hours each week. Restoration of the service levels to five years ago would be an improvement.
Long-term condition e.g. diabetes, arthritis	Doctor was very informative to begin with.
Long-term condition e.g. diabetes, arthritis	Took a long time to get an appointment.
Long-term condition e.g. diabetes, arthritis	The locum GP dismissed my concerns. My own GP contacted me the next day for emergency admission; Without that intervention I could have died.
Long-term condition e.g. diabetes, arthritis	Not taken seriously, had to book several gp appointment until someone listened and sent me for tests.
Long-term condition e.g. diabetes, arthritis	I was sent to PRH A&E by my doctor as there were concerns that I had an infection in a joint where my RA was bad but on arriving there there was not a Rheumatologist to see only an MSK consultant who had no idea about my condition at all. I had bloods done, waited for the results and told everything was ok. Over the next few days things got worse so I went back to my GP who was shocked when he looked at the blood results that had been sent him from the hospital as my ESR and CRP was sky high and I needed treatment immediatly. This was the second time that I have been in this position at the PRH hospital where no one understands RA. Its just shrugged off as a few aches and pains. I feel there needs to be more understanding of this autoimmune condition that affects the body totally different to a normal MSK condition such as oseoarthritis.
Long-term condition e.g. diabetes, arthritis	The support I was given was extremely poor to the extent I am currently in hospital having a toe joint removed after 1 year of neglect. By listening and going to the right clinicians sooner.
Long-term condition e.g. diabetes, arthritis	The condition is eyesight issues which have evolved over the years from 1982 onwards 1982 Acute Glaucoma right eye sight lost in eye 1982 - 2008 regular appointments at eye to make sure it did not come back or appear in the left eye it has not. The left eye is shorted sight only top 3 rows of opticians eye chart. 2008 - 2010 Discharged from eye hospital 2010 onwards new condition in left eye vitreous heemeridging, plus benign tumour in left eye unable to ascertain exact condition probably heredity now under annual reviews at Wolverhampton and Sheffield eye hospitalals
Long-term condition e.g. diabetes, arthritis	I bad to go out of county to get the specialist care as no neurological consultant in Shropshire
Long-term condition e.g. diabetes, arthritis	Many years ago i was not informed of annual check ups etc

Long-term condition e.g. diabetes, arthritis	I had suffered with arthritis for a couple of years before seeking help, this is because it was not too bad to begin with. Once i seeked medical advice it was very easy to get an appointment and with the right GP i was able to have fundamental support.
Long-term condition e.g. diabetes, arthritis	The stroke services in Shropshire are non existence.
Long-term condition e.g. diabetes, arthritis	I wasn't believed by any health professional as I didn't "look" like I was in pain apart from a rash under my skin.
Long-term condition e.g. diabetes, arthritis	Lots of tests they couldn't find out what was wrong with me after numerous visits to different hospitals
Long-term condition e.g. diabetes, arthritis	Meet my needs however an asthma review should be done face to face
Long-term condition e.g. diabetes, arthritis	My partner had a motor bike accident in August 2018. As a result her is now Tetraplegic. During his time in hospital he has been well cared for and had his needs met with dignity and sensitivity. The biggest problem has been the psychological support available to patients in the unit. This was sub-standard and ineffective.
Long-term condition e.g. diabetes, arthritis	Asthma clinics every 3 months are good and supportive. Shouldn't have to pay for prescriptions because its an ongoing condition
Long-term condition e.g. diabetes, arthritis	Anytime I tried to see a doctor I m having to constantly repeat myself. No one is giving me an answer.
Mental health	My GP referred my to IAPT for CBT. I waited over 6 months and when I chased it I was told the referral had been lost. Then they found it but of course I was then added to the bottom of the list. While I understood the CBT approach and have used it since, I think it would have been good to be offered a choice of intervention. I am a very self-aware person and have read a lot of self-help materials. It seems you have to go through a particular route and the system does not take into account individual circumstances. I also think that the medical profession is sometimes too quick to give a medical diagnosis. I think my anxiety and depression were a perfectly normal, healthy response to some very difficult circumstances and I was left thinking there was something wrong with me. My own GP told me I should accept that I would be on anti-depressants for the rest of my life.
Mental health	Depression and anxiety was diagnosed, but there was no discussion of accessing any services that may have been of use
Mental health	I was put on tablets for my depression, when I came off my tablets I felt better, but my depression comes and goes. I've had depression on and off for 8yrs and haven't been offer CBT. I've done some sessions of systematic practice which have been amazing. I think these approach should be offered sooner not left till last.

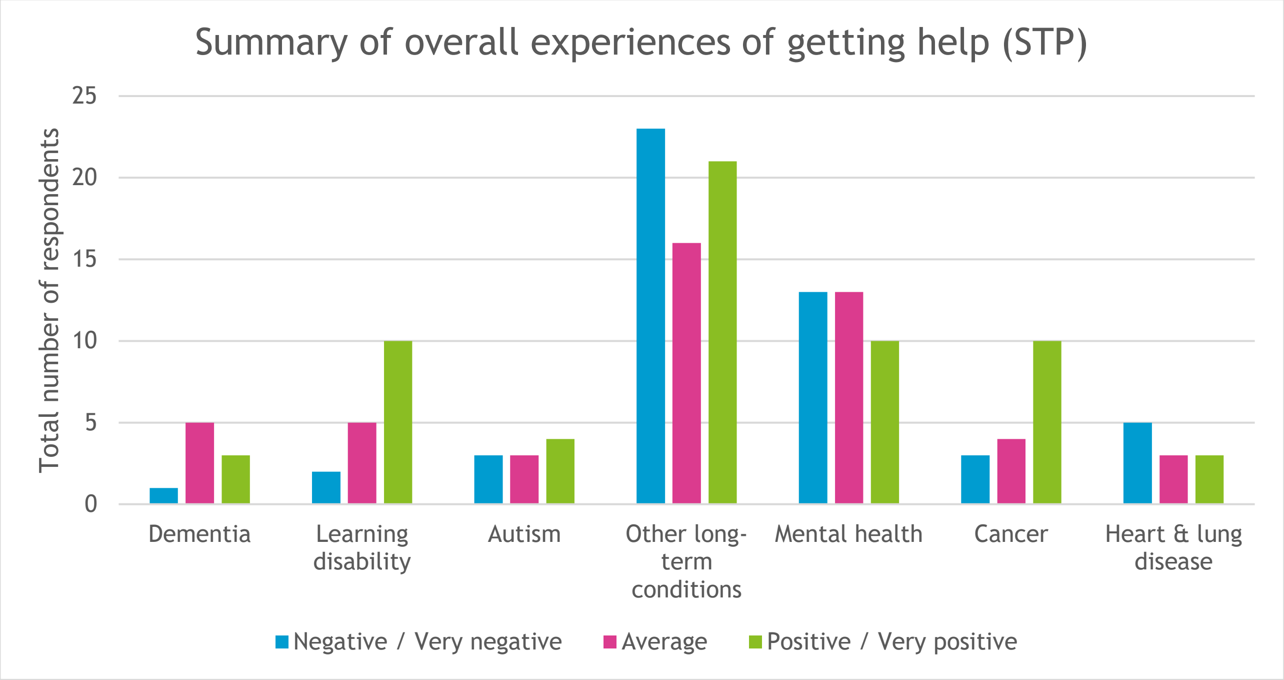
Mental health	A lot of mixed communications between professionals. Support offered was wrong and made me worse and was judged.
Mental health	Yes had very great support, help and understanding from wellbeing centre at Fuller House. Telford.
Mental health	Advised to self refer
Mental health	Daughters clinical psychologist got me the help and now see a consultant clinical psychologist and a mental health OT only way could have improved was the time scale I had to wait
Mental health	Once in the system the support was helpful, but it took a while to get there
Mental health	I always have support with my needs because I had heart problem in the past so I am well and begin proactive and fit and healthy
Mental health	A larger provision at Coral house. Metal health services covering areas such as Selective mutism and chronic anxiety. There is not enough staff providing psychotherapy, speech and language therapy, animal therapy.
Mental health	Need access to services in a better time scale a 6 month wait when you have problems now is not acceptable
Mental health	The waiting times are crazy long and unfair on the people who need help
Mental health	Complex needs require complex answers. You can't just treat everyone the same. What works for one person, doesn't necessarily work for another. Long term support is needed, not quick alleged solutions.
Mental health	I was given leaflets containing information i had already read about online.
Mental health	there was no support, my partner was suicidal and I could not access help for her, eventually, it was a 999 call she made that brought her help. she then spent about three weeks in a mental hospital, she was then sent on weekend leave, with no consideration for my health needs. she then tried to return to the hospital after the weekend and there was no bed. she was sent home for the rest of the week until she saw her Dr on the Friday when she was discharged. again no consideration for my health. her care coordinator said oh he will be fine but I am going on leave today. about 4 days later I was rushed into hospital as one of my health conditions had deteriorated. I phoned the crisis team and left messages, I phoned the mental health team and left messages, all to no avail, during the 8 days I was in hospital my wife was not given any extra support. It did not meet our needs at all.
Mental health	mental health issues very difficult to see someone. long waiting times
Mental health	I feel as though my needs where met
Mental health	There is a huge stigma around mental health. More professionals need training on how to approach and support.
Mental health	The mental health issue I am concerned with is substance misuse and addiction. Since the Treatment Agency was abolished in 2010, services in this area have been progressively cut and outsourced. This means that access is limited, treatment is fractured and accountability is next-to-nowhere.

Mental health	The support met my needs for about a year. After personal circumstances the support couldn't be adjusted to suit my needs.
Mental health	The support met my needs for about a year. After personal circumstances the support couldn't be adjusted to suit my needs.
Mental health	No it did not meet our needs as it got thrown out by CAMHS and after this my child mental state has got worse and has since said he wants to end his life an has self-harmed
Mental health	I need support to help me improve my home life. I was told by my social worker to get mental health support from my GP. I tried many times and got cut off by Teldoc.
Mental health	The patient, who is now 81, has experienced mental health problems since childhood. When she suffered a severe setback last summer, the initial contact was OK, but was not followed through. She now has an appointment for an assessment at the end of May. In the meantime, she has been suicidal at times.
Mental health	I have been diagnosed with fibromyalgis and depression. I believe i have had symptoms for over 20 years but only had a diagnosis in 2016. I have found the support for this condition very limited. However regarding depression i do think the services have improved over the last 20 years.
Mental health	GP support was excellent, treatment including CBT was superb and supported me through the issues and gave me the tools to manage my condition. HOWEVER I was very lucky at the time to have Company BUPA which enabled my GP to get me immediate access rather than the 12 month wait at the time. If I hadn't been lucky to access immediately it would have drained NHS resources and worsened my condition with lack of available treatment
Mental health	Rarely get to see the same GP twice and long waiting lists for treatment.

7. How would you describe your overall experience of getting help?

How would you describe your overall experience of getting help?

	Shropshire	Telford & Wrekin	Grand Total
Very negative	11	8	19
Negative	15	16	31
Average	20	29	49
Positive	15	26	41
Very positive	13	7	20
Don't know		1	1
Blank	3	1	4
Grand Total	**77**	**88**	**165**



8. Do you have any other/additional conditions including long term conditions or disabilities?

- Yes: 82
- No: 78
- Blank: 5

9. If so, how would you describe the experience of seeking support for more than one condition at a time?

If so, how would you describe the experience of seeking support for more than one condition at a time?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
It made it harder	20	31	51
No difference	7	9	16
It made it easier	3	3	6
Don't know	3	2	5
Not applicable	2	2	4
Grand Total	**35**	**47**	**82**

The health and care support you received after initially seeking help

10a. How would you describe the time you had to wait to receive your initial assessment or diagnosis?

How would you describe the time you had to wait to receive your initial assessment or diagnosis?			
	Shropshire	Telford & Wrekin	Grand Total
Very slow	18	21	39
Slow	20	23	43
Ok	14	26	40
Fast	11	7	18
Very fast	6	6	12
Don't know	5	2	7
Blank	3	3	6
Grand Total	**77**	**88**	**165**

10b. Please tell us more about the length of time you waited [free text]

Autism	My daughter waited 2.5 years for a diagnosis of autism during that time she was refusing school and self harming. However, her dyspraxia diagnosis was fast and support was great.
Autism	Waited over 2 years just to get first appointment
Autism	Diagnosis can take several years and often you feel and that your options don't matter.
Autism	We were refused an appointment by childrens mental health for 3 years, this was despite school & council support.
Autism	Felt like I was passed around from person to person
Autism	I have a social worker and support worker. I have good relationship with them but most support is form family.
Autism	I suppose as a parent you would like things to be done there and then so to us it felt like a lifetime waiting for the answer, however I appreciate the appropriate assessments and emotional testing needed to be done. Also, her age was a big factor they didn't want too diagnose too early incase she developed differently
Autism	it took 6 months for initial paediatrician appointment and a further 6-8 months for CDC referal. If done earlier i could of got my son into a sen nursery before starting reception
Autism	It was all done quickly.
Cancer	my diagnosis had to stop as priority was given to another health condition that I was experiencing at the time. When I was finally diagnosed with several

	conditions the main one was told to me verbally I found the rest out by receiving a letter which stated fibromyalgia and other conditions.
Cancer	2 week rule. Very quickly seen and diagnosed with breast cancer
Cancer	Once the diagnosis had been made the chemo started soon after. I will not say anything about the qeh they were really good. The gp side was dreadful
Cancer	several months to get an appointment
Cancer	She was rediagnosed in July and she died in October
Cancer	Didn't wait long
Cancer	I did not wait very long from being told I had cancer to surgery just feel disappointed how far I have to travel and cost.
Cancer	Diagnosis imparted very quickly.
Cancer	tried to get clue badge due to pain walking but was rejected because she walked 50 yards without stopping but eventually got one because vascular dementia was confirmed. Had 5 biopsies before cancer was confirmed after 15 years of examinations and treatments.
Cancer	1/2 weeks
Cancer	1/2 weeks
Cancer	We had to wait slightly longer than normal because the diagnosis was made over the Christmas period
Cancer	Failure of the primary care sector (GP) to recognise the underlying problem, concentrating on the obvious - responding to a failure to respond to prescribed pain control by increasing the dosage and prescribing a stronger drug. After visits to TWO of my GPs and resorting to a visit to Kidderminster MIU, it was the paramedic who attended the emergency call out by my wife who insisted I be taken to hospital because he suspected there was something more seriously wrong than "a bad back"!
Dementia	Took ages for Mum to be seen by Memory Clinic .
Dementia	Over a year before we got any help
Dementia	5 months
Dementia	Seemed to take a long time from test to having results
Heart and lung diseases	Up to two years and unecessary hospitalisation.
Heart and lung diseases	Appointments for referrals to arthritis specialist was very long and then dismissed following scans. Condition now worse have to start again.
Heart and lung diseases	My second long term health condition has been a more positive experience than my cardiac health issue.
Heart and lung diseases	Quickly as private medical insurance

Heart and lung diseases	Was a reasonable time to be referred to local Hospital. No experiance of my condition and hence incorrect diagnosis and no treatment until referral to specialist centre
Heart and lung diseases	Poor initial diagnosis meant no treatment for two days which could have killed me
Heart and lung diseases	I didn’t I went straight to X-ray told to see my dr straight away. Saw a Consultant in 2 weeks many tests later a diagnosis within a month excellent. Not so now though
Learning disability	LONG TIME
Learning disability	My son has learning difficulties and hyper mobility but feels like they can only help with one thing at a time
Learning disability	Months
Learning disability	Waited 3.5 years!!!!
Learning disability	They called or sent a letter asking me to come in
Learning disability	Born with Downs
Learning disability	Instant "formal diagnosis" was a few weeks
Long-term condition e.g. diabetes, arthritis	Early stages of mesh complications from TVT in 2016. Referral just going off to Manchester and an immunologist.
Long-term condition e.g. diabetes, arthritis	Four years.
Long-term condition e.g. diabetes, arthritis	It was more than a year. Had it been sooner, ie within the first three months, I would have had a chance of a full recovery. In the end it was myself who suggested to my doctor that what I had might be ME/CFS after I'd had a chance conversation with someone who had a friend with similar symptoms who had been diagnosed. Fortunately I had a GP who cared enough and listened to me and went down that line of inquiry. More effective research into the condition and greater education of the medical profession generally about the condition is desperately needed especially as the current NICE guidelines are not adequate.
Long-term condition e.g. diabetes, arthritis	I was diagnosed 50 years ago so this question is not entirely relevant.
Long-term condition e.g. diabetes, arthritis	A few days
Long-term condition e.g. diabetes, arthritis	Once the illness was identified the people required to help were contacted, appointments were made, medication prescribed

Long-term condition e.g. diabetes, arthritis	I was diagnosed with ME/CFS after 3 months. A reheumatologist agreed that it probably was. This was in 1996. This made a great difference as I was advised to only do 10% more in a month - though didn't as no social support so ended up losing my career as a teacher. A meeting with the CCG recently said that GPs are reluctant to diagnose ME because it labels people. My experience says different. And this DOES NOT mean that other conditions can't be tested.
Long-term condition e.g. diabetes, arthritis	For some operations waited up to a year. To get eye treatment had to go private as I would have hardly any sight as NHS service wait forinitial assessment was above 18 weeks. To get physio over 6 weeks, to get injections (i.e. cortisone) over 8 weeks. For one operation took 15 months from initial assessment so I had to have a bigger operation.
Long-term condition e.g. diabetes, arthritis	I haven't seen a consultant self managed with pain killers for 30 years
Long-term condition e.g. diabetes, arthritis	A few hours
Long-term condition e.g. diabetes, arthritis	From memory I think it was within a few weeks.
Long-term condition e.g. diabetes, arthritis	waited a year for a diagnosis of arthritis of the knees and 4 months for a diagnosis of Osteoporosis
Long-term condition e.g. diabetes, arthritis	See above comments
Long-term condition e.g. diabetes, arthritis	My Gp was brillant
Long-term condition e.g. diabetes, arthritis	As stated, the length of time was too long. I have only recently been diagnosed 2 years after giving birth.
Long-term condition e.g. diabetes, arthritis	Had to go private
Long-term condition e.g. diabetes, arthritis	I was too small to remember when this happened
Long-term condition e.g. diabetes, arthritis	I had a 15cm ovarian cyst. My gp told me I was depressed so wouldn’t refer me for any help. I had a brain scan which showed lesions and was unable to get a neurologist locally.
Long-term condition e.g. diabetes, arthritis	Still waiting

Long-term condition e.g. diabetes, arthritis	Was never diagnosed properly due to medical records having some false info
Long-term condition e.g. diabetes, arthritis	It took about 6 month initially
Long-term condition e.g. diabetes, arthritis	Immediate help and sent straight to hospital following our daughter’s diagnosis of diabetes.
Long-term condition e.g. diabetes, arthritis	8 months between GP referral and first hospital appointment
Long-term condition e.g. diabetes, arthritis	My GP responded very quickly. But further investigation included a misdiagnosis
Long-term condition e.g. diabetes, arthritis	My first long term condition was very fast because services were just opening up in the early 80's it was marvellous. My 2nd long term condition started in 2000 and it took much longer but that was initially the first GP's fault.
Long-term condition e.g. diabetes, arthritis	Took too long
Long-term condition e.g. diabetes, arthritis	Waited around 4 months for inital diagnosis, due to mis communication from doctors.
Long-term condition e.g. diabetes, arthritis	Had to wait weeks for each stage to establish diagnosis and took several months overall before practical intervention was started.
Long-term condition e.g. diabetes, arthritis	1 month - average 4 weeks.
Long-term condition e.g. diabetes, arthritis	Bone marrow biopsy on Monday, results Thursday.
Long-term condition e.g. diabetes, arthritis	I had to get in touch with PALS 14 weeks to receive pill cam results confirming Crohn’s Parkinson’s diagnosis less intrusive but still took a while understandable. I have
Long-term condition e.g. diabetes, arthritis	Initial assessment took too long as no one listened. Eventually they took samples. When results of that sample came back negative, they didn't want to do any further tests yet was still suffering with symptoms of daily diarrhoea several times a day. Had to book another appointment where they sent me for a colonoscopy and referred me to a specialist.
Long-term condition e.g. diabetes, arthritis	I had to get in touch with PALS 14 weeks to receive pill cam results confirming Crohn’s Parkinson’s diagnosis less intrusive but still took a while understandable. I have

Long-term condition e.g. diabetes, arthritis	I waited for 4 hours even though my GP had phoned A&E before hand
Long-term condition e.g. diabetes, arthritis	1 year
Long-term condition e.g. diabetes, arthritis	The Glaucoma back in 1982 which was my first serious eye condition was effective straight to hospital after seeing my local GP at the time
Long-term condition e.g. diabetes, arthritis	I managed to get an appointment within 2 weeks.
Long-term condition e.g. diabetes, arthritis	After speaking to the stroke nurse a referral was made to the physios about difficulty swallowing and choking it took some time to get an appt and then to be told it happens
Long-term condition e.g. diabetes, arthritis	Took 4 years to get seen by the relevant professional got diagnosed and discharged. I had to fight my Gp with legal action if he didn't refer me to the relevant specialist I had help from a metabolic support charity
Long-term condition e.g. diabetes, arthritis	Nearly two years
Long-term condition e.g. diabetes, arthritis	One month
Long-term condition e.g. diabetes, arthritis	Waiting times are ridiculous - way too long
Mental health	As I explained above, when I chased after 6 months of waiting I was told my original referral had been lost. Then it was suddenly found. It seemed abit inplausable and made me question the trust worthiness of the service. Not a good start when receiving support for mental health issues. I would prefer it if services were honest and realistic about their waiting times.
Mental health	I have not yet seen a consultant about the condition I have, I'm having to chase them up
Mental health	Months
Mental health	One month from first being diagnosed.
Mental health	Had to wait a year to get the right help
Mental health	Not long but sometimes it take ages
Mental health	Mental health. Suicidal thoughts. 3 month wait until 1st appointment. - too long. There needs to be something to for people to access when they are so low - and children.

Mental health	I'm on month 9 now and still waiting!
Mental health	More then 6 months
Mental health	contacting the crisis team was useless, they didn't want to know as my wife was not engaging with psychiatric services. it took a 999 call to start getting help
Mental health	Weeks/months
Mental health	waited a month to see someone
Mental health	It was fairly quick. Reasonable.
Mental health	I had to keep chasing referrals
Mental health	If you have more than one condition, as many elderly people have, it is hard to get specialists in one field to recognise the interdependence of the whole person, they are really only concerned with their "bit" of you! I am one whole woman!
Mental health	The referral took approximately 6 months before being accepted with CAMHS (now known as BEEU)
Mental health	The referral took approximately 6 months before being accepted with CAMHS (now known as BEEU)
Mental health	5 - 6 years
Mental health	Still waiting for the help and support I require
Mental health	3 weeks for a phone call, then another 2 - 3 weeks before anybody came.
Mental health	4 months.
Mental health	Mental Health GP access excellent , CBT on accessible quickly due to having BUPA. NHS waiting time was over 12 months. COPD/Asthma excellent GP support and signposting including support and help .
Mental health	Help with medication was timely and helpful. Wait for talking therapy was nearly a year.

11a. How would you describe the time you had to wait between your initial assessment/diagnosis and receiving treatment?

How would you describe the time you had to wait between your initial assessment /diagnosis and receiving treatement?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Very slow	12	14	26
Slow	18	23	41
Ok	21	24	45
Fast	8	16	24

Very fast	9	5	14
Don't know	6	3	9
Blank	3	3	6
Grand Total	**77**	**88**	**165**

12 After being diagnosed or assessed, were you offered access to further health and care support?

- Yes (Go to Q13): 69
- No (Go to Q15): 90
- Blank: 6

13. If you accessed support, what aspects worked well? [free text]

Autism	Counselling from Heckos. She didn't engage well and the counselling stopped with no alternative offered.
Autism	Regular visits
Autism	we had further help with EHCP, The use of PECs and help getting him into a special needs school when he started full time school which was very fast excellent support
Autism	SALT and OT, help from Health Visitor
Cancer	only the Macmillan nurse. They visited once. And to be perfectly honest when I see the advert I get really angry. I have had 3 sisters die 2 recently and had no help whatsoever
Cancer	specialist nurses
Cancer	Adult social care and Hospice all very good and responded quickly. GP support very good. Cares centre also very supportive.
Cancer	My CN nurse was lovely and got back to me with my concerns very quickly being
Cancer	As son worked in care certain avenues became apparent to me and my wife. Certain items like stairlifts, wheelchairs we purchased ourselves along with hygiene points. Eventually we had carers morning and evening supplied by Helping Hand for the last few months of her life.
Cancer	Hamar centre Shrewsbury/ cancer services
Cancer	Hamar centre Shrewsbury/ cancer services
Cancer	Skill of medics in getting my medications right.
Dementia	Leaflets given at time
Heart and lung diseases	Received help through investigations, heart clinic, pacemaker monitored on the phone, got fall alarm, disabled parking, OT & Physio assessments - all happened in timely fashion, quite a bit was organised through the private medical care

Heart and lung diseases	Fortunately after a couple of years at the local hospital a registrar assessed me and correctly referred me to a specialist unit in an out of area hospital.
Heart and lung diseases	Stoke support was exemplary, support from Shrewsbury after discharge had to be faught for by Stoke!
Heart and lung diseases	Gamer centre at SATH
Learning disability	GOOD DRS
Learning disability	Good thorough HCheck at the doctors are good they sign I can understand / they take time
Learning disability	All
Learning disability	Personal tutor
Long-term condition e.g. diabetes, arthritis	Not yet accessed
Long-term condition e.g. diabetes, arthritis	1) 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. 2) The Inner Gardens Project - a wonderful art based group which ran for little over a year designed for people with ME/CFS run by the Shropshire ME Support Group, Shropshire Wildlife Trust and Keele University which gave me a sense of identity and life beyond my condition despite me having little artistic ability. 3) Some counselling which helped me come to terms with my condition and the fact that all my hopes and dreams for myself had been torn up and I had to find a new way of living. Firstly in one to one sessions of talking and art therapy held at Cotesloe House, Shrewsbury? and then in a group at Hamar House Royal Shrewsbury Hospital for people with Cancer and other long term conditions and their carers run by Lin Brown. 4) Sessions with a dietitian and with a physiotherapist at the RSH also showed me ways of dealing with my condition. 5) A very helpful and caring GP who took me seriously and was willing to try things to see if they worked including herbal medications and such and who referred me to the Inner Gardens Project and to the Hamar House sessions. Since her retirement I haven't had such support.
Long-term condition e.g. diabetes, arthritis	support to have in the community
Long-term condition e.g. diabetes, arthritis	They knew of me and my needs
Long-term condition e.g. diabetes, arthritis	They all were accessed in a similar progression. Doctors appointment, medical consultant, course of medication

Long-term condition e.g. diabetes, arthritis	None of the aspects worked well as had to wait too long to access them.
Long-term condition e.g. diabetes, arthritis	I have been referd to physio but awaiting my appointment.
Long-term condition e.g. diabetes, arthritis	Meeting others with ME and swapping ideas for coping.
Long-term condition e.g. diabetes, arthritis	Just working the two conditions
Long-term condition e.g. diabetes, arthritis	This question is somewhat misleading - the individual receives ongoing treatment for their condition but has not been offered support outside their treatment regime.
Long-term condition e.g. diabetes, arthritis	Hydrotherapy
Long-term condition e.g. diabetes, arthritis	I hope this is the second long term condition because in the 80's things were much quicker and you go to see a specialist and all the treatments very quickly.
Long-term condition e.g. diabetes, arthritis	Education and provision of helpful intervention
Long-term condition e.g. diabetes, arthritis	Ibd nurse x2.very quick to respond. Initially Parkinson’s used to have 2 nurses, and they were excellent but1 left and has not been replaced 1is not enough ! Need 2nd Parkinson’s nurse!
Long-term condition e.g. diabetes, arthritis	Ibd nurse x2.very quick to respond. Initially Parkinson’s used to have 2 nurses, and they were excellent but1 left and has not been replaced 1is not enough ! Need 2nd Parkinson’s nurse!
Long-term condition e.g. diabetes, arthritis	Going to Podiatry 4 times who wouldn’t touch me because of my long term conditions and medications, then forgetting about me, disgraceful.
Long-term condition e.g. diabetes, arthritis	Receiving acute hospital care
Long-term condition e.g. diabetes, arthritis	Community support
Long-term condition e.g. diabetes, arthritis	Aids to assist me to be mobile and safe

Long-term condition e.g. diabetes, arthritis	Clinics - monitor breathing. Open and trying different types of asthma meds
Mental health	The 1:1 CBT work
Mental health	Being referred to therapy
Mental health	One to one session
Mental health	CBT therapy
Mental health	My health and well-being
Mental health	offered a psychotherapist - but after a few months - was told the department was being rearranged and her job was no longer available - given one weeks notice. Then 3 months wait until another therapist - she left for another job after 2 sessions, then another 3 month wait, next lady we received 8 sessions then she left for another job - it has been 5 months since she left - ive been told to write to the service manage at Coral house Shrewsbury to complain, by staff at Coral house!
Mental health	she was an inpatient in the psychiatric unit. she was very ill and she didn't want me as her prime carer to be involved so I wasn't allowed any input. so a lot of her problems were not addressed. the design of the ward is highly dangerous, It has been designed so the staff cannot overlook the patients. Total insanity. the patients are in the ward because they are very ill and need to be watched over. At night if the patients feel they need to talk to the staff they are sent back to their rooms as it is deemed not apropriate to talk with patients overnight
Mental health	Being listened to and being kept in the loop
Mental health	once the treatment cbt it was ok.
Mental health	When I needed surgery the system worked fast and efficiently in spite of a misdiagnosis I did recieve the treatment I needed. An apology for the misdiagnosis and unnecessary operation would have been nice, though.
Mental health	Counselling didn't work well
Mental health	Accessible "in house" counselling, which sadly has now been stopped.
Mental health	GP support and knowledge plus Pulmonary Rehab Course to self manage EXCELLENT

14. If you accessed support, what aspect could be improved? [free text]

Autism	Face to Face would have been better than online. Choice of alternative counselors should be given.
Autism	Better communication Between various departments
Autism	it would of been great to get on the autism early bird course to help us understand we are yet to go on this 12 months on
Autism	Speach and language at home sessions.

Cancer	To be perfectly frank I think they are a complete waste of time
Cancer	vital information about services was often missing
Cancer	To be given a email address sending photos of my wound and showing them might save me a trip to stoke. Even being able to face time
Cancer	In PRH July, wife had some treatment and home carers was arranged but not always at the same times and lasted for 3 weeks. In Sept 2017 was again at A+E PRH and then transferred to Whitchurch for one week, care was implemented again but times varied. (NAME REMOVED) organised new care which was more convenient this started 16th November 2017 and lasted until late February 2018 at wife's death.
Cancer	Just a phone call to ask how we are !
Cancer	Just a phone call to ask how we are !
Cancer	Macmillan nurses excellent, but over-keen to install support equipment that wasn't really needed. They anticipated need rather than responded to it.
Heart and lung diseases	GPs having more access to knowledge of areas that specialist centres deal with, so that the initial referral can be direct. Save time, money and safer for the patient
Heart and lung diseases	Specific physio for condition instead of being pushed into cardiac physio which was not required
Heart and lung diseases	They couldn’t do anything else
Learning disability	More support through the years as they age and things change
Learning disability	It was good help
Learning disability	More than happy
Long-term condition e.g. diabetes, arthritis	Follow ups. With a long term condition it seems that after initial help everything goes silent and you are left on your own to get on with it. This doesn't take into account that things change over time or that there are new ways of dealing with things which come to people's attention. Help and support seems to rely on the patient going to see the already overworked GPs with a specific symptom. This leaves you feeling isolated and forgotten, and when it comes to filling in WPD forms etc means that it looks like you aren't particularly ill whereas it just means that you are the same or even a bit worse. Because I also have asthma I get to see a nurse every year and there is a review of my medicines each year but no one sees me specifically for my ME/CFS. Because I asked to see a consultant who has an interest in ME/CFS I do have some support which other people I know with the condition do not have but the consultant is hard pressed as he seems to be the only person at that level with such an interest and he is actually a geriatric consultant rather than a specialist in ME/CFS. A proper ME/CFS (and perhaps Fibromyalgia and Lupus?) Clinic would make a huge difference as they could guide people with pain management and other things to help live with these conditions and be at the cutting edge of what treatments do emerge from current research (as well as providing researchers with subjects for such clinical trials and other knowledge of the diseases?). This would also enable people to feel less abandoned after their initial diagnosis as it could be on-going assessment and support.

Long-term condition e.g. diabetes, arthritis	More informed of waiting times
Long-term condition e.g. diabetes, arthritis	Anything that requires funding! by careful analysis the money will not help support
Long-term condition e.g. diabetes, arthritis	Waiting times and to be listened to, felt age (being able) it was considered I am not important when of course quick access would bep reventative treatment, lessen need for more extensive treatment. Having to wait seriously affected my mental health
Long-term condition e.g. diabetes, arthritis	Shorter times for meetings, more local support.
Long-term condition e.g. diabetes, arthritis	Sad to say but there £="English" speaking. They were hard to understand
Long-term condition e.g. diabetes, arthritis	For hydrotherapy with a physiotherapist to be continued.
Long-term condition e.g. diabetes, arthritis	In those days nothing BUT now its dreadful one just has to have patience and wait BUT keep your eye on the progress because you have to stand up and be counted and ring if you don't hear anything within say 6 weeks.
Long-term condition e.g. diabetes, arthritis	Tailoring of intervention to individual circumstances and trying different options if first solution does not work. I was fortunate that time and trouble at first therapeutic contact gave me the correct solution, but am aware of others who were left without ongoing practical support after first option "failed".
Long-term condition e.g. diabetes, arthritis	See previous
Long-term condition e.g. diabetes, arthritis	See previous
Long-term condition e.g. diabetes, arthritis	Having trained staff who has had allot of experience dealing with patients with comp,ex needs.
Long-term condition e.g. diabetes, arthritis	At this stage no improvement were required to help and support
Long-term condition e.g. diabetes, arthritis	Quicker and more information
Mental health	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.
Mental health	having follow ups from doctors
Mental health	None
Mental health	My mental health
Mental health	Staff trained in the areas of the problems people have, so they have understanding, and the capabilities to help.
Mental health	Waiting to speak with a counselor
Mental health	quicker response time
Mental health	Better communication!! I think that as so many "back office" staff have ether been removed and outsourced, (eg appointments services) it is not unknown to receive the letter AFTER the actual appointment time! It is not the wait for treatment, but the wait to see a consultant which is too long. We know why!
Mental health	My friend attended counselling but found it hard to make appointments with working full time and appointments only being offered during office hours
Mental health	More help dealing with adjustments and emotional side of a long term condition. Advice on lifestyle
Mental health	Bring back "in house" counselling
Mental health	Make it readily available and save the NHS money rather than the lottery of where you are
Mental health	More information about when I will be seen.

15. Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist

- Yes (If yes, go to Q16): 95
- No (If no, go to Q17): 65
- Blank: 5

16a. How would you describe the time you had to wait between the initial appointment and seeing the specialist?

How would you describe the time you had to wait between initial appointment and seeing the specialist?

	Shropshire	Telford & Wrekin	Grand Total
Very slow	7	10	17
Slow	10	6	16
OK	19	17	36
Fast	3	6	9

Very fast	7	2	9
Don't know	2		2
Blank	2	4	6
Grand Total	**50**	**45**	**95**

16b. Please tell us more about the length of time you waited [free text]

Autism	At least 18 months if not morev
Autism	Still had to wait 9 months
Autism	It was not as fast.
Cancer	It was very quick all the staff were brilliant and got me seen very quickly to see the specialists and then I was referred to physiotherapy and hydrotherapy.
Cancer	Less than 1 week
Cancer	about 3 weeks+
Cancer	Appointments came through fast.
Cancer	Had to wait a week not to bad luckily my local doctor prescribe me more antibiotics while am waiting
Cancer	4 Monthly checks for arthritis. Dementia - good waiting times from doctor to memory clinic and scan. Cancer- fast but was terminal and operation/chemo impossible due to dementia
Cancer	We saw the specialist as soon as my husband was diagnosed
Cancer	Haven't really had to wait!
Dementia	As above
Heart and lung diseases	The first referal to a specialist took 2 months, now I contact the specialist secretary to arrange appointments.
Heart and lung diseases	Private Medical insurance
Heart and lung diseases	Was 4 years to see the correct specialist
Heart and lung diseases	Sorry I can't remember as I have had this condition since birth
Heart and lung diseases	Good at Stoke
Heart and lung diseases	2 weeks
Learning disability	Not sure my family sort

Learning disability	VERY LONG TIME
Learning disability	I waited over 6months to finally see someone
Learning disability	12 months
Learning disability	Don't know
Long-term condition e.g. diabetes, arthritis	For the autism still waiting 6 months later. For mesh complications referral went off this week.
Long-term condition e.g. diabetes, arthritis	A few weeks but a follow up scan to confirm the condition was reversed was refused due to weight loss
Long-term condition e.g. diabetes, arthritis	It was about a month. The Consultant I see now I only got to see because someone told me about him and I asked my GP if I could be referred. This was some 10 years after my initial diagnosis confirmation in 2003 by a consultant who didn't really know much about ME/CFS - I was among his last appointments before retiring - with whom I spent about 10 minutes and who simply agreed with what my then GP told him.
Long-term condition e.g. diabetes, arthritis	We have been contacted within days of the orginal consuktation
Long-term condition e.g. diabetes, arthritis	As mentioned before often waiting 18 weeks or more
Long-term condition e.g. diabetes, arthritis	Procedure for physio referral was not carried out on time which caused a delay to recovery. Consultants / Registrars need to ensure they complete the relevant paperwork
Long-term condition e.g. diabetes, arthritis	Once eventually referred to tissue viability the length of time was ok but it took years to get the help my aunt needed
Long-term condition e.g. diabetes, arthritis	Time was ok Consultant not. I ended up going private as getting unhelpful comments.
Long-term condition e.g. diabetes, arthritis	Was told I was depressed not ill. I'm depressed BECAUSE I'm ill, not the other way roundz
Long-term condition e.g. diabetes, arthritis	First time over 6 weeks, scond over 8
Long-term condition e.g. diabetes, arthritis	About 8 weeks
Long-term condition e.g. diabetes, arthritis	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.

Long-term condition e.g. diabetes, arthritis	The initial appointment was with the specialist.
Long-term condition e.g. diabetes, arthritis	It is too long ago to remember.
Long-term condition e.g. diabetes, arthritis	In the 80's fast but now over 6 weeks .
Long-term condition e.g. diabetes, arthritis	7+ weeks as only one consultant covered this condition at that hospital
Long-term condition e.g. diabetes, arthritis	Seen immediately
Long-term condition e.g. diabetes, arthritis	Seems like ages when you are scared and in pain
Long-term condition e.g. diabetes, arthritis	Tests took a long time to come back. When they did the specialist told me I had crohns. No further treatment, dietician referral or anything for nearly a year. Went back to my gp a few weeks ago, I was told wrong. I have IBS and have been given a prescription which seems to be working so far and given information about a dietician. This has spanned over 2 years, this could have been worse.
Long-term condition e.g. diabetes, arthritis	Seems like ages when you are scared and in pain
Long-term condition e.g. diabetes, arthritis	8 weeks then 12 weeks
Long-term condition e.g. diabetes, arthritis	Full details of that stage I cannot remember exactly as I saw lots of people at that stage as I was an inpatient
Long-term condition e.g. diabetes, arthritis	My condition develops slowly slow response creates anxiety
Long-term condition e.g. diabetes, arthritis	With diabetes there are several areas which are affected. Having to go for separate appointments for eyes, feet, diet all adds up. I take mom mom to all of theses taking time off work. Waiting over 2 hours for an appointment is not acceptable. Text me when the appointment will be.
Long-term condition e.g. diabetes, arthritis	Whilst awaiting referral to specialist I received a phone call, accepting my physio referral I had no idea what the lady was on about until she told me what it was for. It's was 9 months after the referral was made.

Long-term condition e.g. diabetes, arthritis	6months
Long-term condition e.g. diabetes, arthritis	About 6 weeks
Long-term condition e.g. diabetes, arthritis	One every two months I have a specialist appointment. Sometimes it cancels last mintue
Mental health	A couple of weeks because I saw the Trainee rather than the Psychiatrist.
Mental health	It's been 18mths since I was told I carry a condition, supposed to have seen someone hasn't happened, in the process of chasing them
Mental health	Months
Mental health	Not long but I waited ages
Mental health	3 to 4 months
Mental health	Again took months
Mental health	it was direct access as admitted to a psychiatric ward
Mental health	Varies
Mental health	month
Mental health	I recently had to wait for five months for a specialist NHS dental appointment. (I had been offered a private and very expensive consultation within a week!)
Mental health	A few weeks
Mental health	Just under a year.

17. If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

	Shropshire	**Telford & Wrekin**	**Grand Total**
Very difficult	19	8	27
Difficult	13	20	33
OK	13	28	41
Easy	12	5	17
Very easy	6	10	16

Don't know	4	8	12
Not applicable	7	9	16
Blank	3		3
Grand Total	**77**	**88**	**165**

18a. Did the support option you were offered meet your expectations?

Did the support options you were offered meet your expectations?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
No	30	32	62
Somewhat	12	30	42
Yes	24	24	48
Blank	11	2	13
Grand Total	**77**	**88**	**165**

18b. Please explain how the care did or did not meet your expectations and how it could have been improved. [free text]

Autism	Didn’t really tell me anything I didn’t already know
Autism	It is difficult to obtain diagnosis and then there is a lack of follow up support or sign posting to services.
Autism	We saw the doctor every 6 months, there was no other support offered. We sourced our own support.
Autism	We were given lots of info but no one to guide us through lots of information felt abit left after diagnosis until my son started attending special needs school know we feel more supported
Autism	It helped my son a lot. The CDC people were brilliant, and those who did the MDA.
Cancer	I needed counselling but was not offered it. I was offered physiotherapy and then hydrotherapy the teams there were great and really looked after me.
Cancer	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.
Cancer	As above

Cancer	Not enough specialist nurses, you don't know when they might be able to return your call
Cancer	Once she was diagnosed they did not offer any more treatment as it was too aggressive so it seemed to just be a waiting game
Cancer	More specialist nurses for people with Dementia who have diagnosis of Cancer as well.
Cancer	My care was ok I just feel more local support would be better.
Cancer	Oncology service was efficient and prompt.
Cancer	In first two instances of care times varied between 0800 and 1100 hours which meant I was doing washing/breakfast and night bedtime duties on many occasions. Care arrange by (NAME REMOVED) was very good and we had an excellent team.
Cancer	Clinical nurses need to follow up get in touch just ask how are we doing!!!
Cancer	Clinical nurses need to follow up get in touch just ask how are we doing!!!
Cancer	The care was excellent in the clinic & on the ward. Occasional admissions to A & E were difficult due to length of waiting time etc. More attention should be given to cancer patients, when attending A & E.
Cancer	Exceeded - to excess (see above)
Dementia	Limited Care Respite Breaks increased Pressure on Care and Family Regular Respite breaks would have greatly improved Carers Physical and Emotional Health. Admiral nurse when allocated were excellent
Dementia	No GP visits, very little support in house
Dementia	Admiral nurse
Heart and lung diseases	I found out about it myself and asked to be referred.
Heart and lung diseases	I excepted to get more help for my arthiritis. Have been dismissed.
Heart and lung diseases	Again I can't have the necessary surgery to removed my gallbladder because of my cardiac condition, which also can't be operated on.
Heart and lung diseases	The support systems are less effective when the person also ha a mental health issue
Heart and lung diseases	Had to travel long distances
Heart and lung diseases	Care is specific for my long term health conditions and excellent.

Heart and lung diseases	Stoke were excellent
Heart and lung diseases	I didn’t think having my extended family brought in would make a difference.
Learning disability	Explain things. I have an advocate. I have a (shared lives) carer they help.
Learning disability	I get support from family and staff
Learning disability	My son got a diagnosis and that was it I have no idea what to expect or what help we can get
Learning disability	mum and dad support me
Learning disability	They could not have done anymore
Learning disability	I was able to speak to my youth worker whenever needed it
Learning disability	More options available
Learning disability	Okay
Learning disability	Very happy with my care
Learning disability	It met all my needs. I was given a tutor who I could contact whenever and had appointments regularly. I had technology given to me and out on to my laptop to help with uni work
Long-term condition e.g. diabetes, arthritis	Still waiting to see specialists. No support in place as yet.
Long-term condition e.g. diabetes, arthritis	I believe that the system is only geared up for acute care needs and that ridiculously lifestyle advice is never considered. Only magic bullet medications that treat symptoms, not cures.
Long-term condition e.g. diabetes, arthritis	Told lots of support available but not where to obtain it.
Long-term condition e.g. diabetes, arthritis	This is difficult to answer because, obviously I hoped that I would be cured and that is not the case (though had I been diagnosed earlier I would have stood a much better chance of such a recovery). I feel just about everyone did their level best given the paucity of knowledge about this condition - especially at that time. In other instances, such as surgery on my feet, I have been delighted that there was knowledge of ME/CFS shown by the anesthetist, surgeon and nurses and the condition being taken into account for my treatment (eg a spinal anesthetic rather than a general one). I do think that a specialist clinic as I suggested above would be a good way of providing on-going and effective support for this and similar conditions - especially as specialist consultants/doctors would be able to give much faster diagnoses and so increase the chances of people actually recovering or recovering to a greater extent than is currently the case. It would also massively decrease the feeling of isolation and helplessness often experienced to have such dedicated support easily accessible.

Long-term condition e.g. diabetes, arthritis	No access to a telephone to ring with problems
Long-term condition e.g. diabetes, arthritis	When the futre looks bleak, the care available at the time of this bleakness met all our needs.
Long-term condition e.g. diabetes, arthritis	Not offered any treatment for ME/CFS. So there were no expections!!!!
Long-term condition e.g. diabetes, arthritis	Physiotherapy so that joints didn't deteriorate so much
Long-term condition e.g. diabetes, arthritis	GP not willing to discuss other options other than medication I was on
Long-term condition e.g. diabetes, arthritis	No help offered apart form nurse led clinic which was too basic
Long-term condition e.g. diabetes, arthritis	No support options - left to research myself
Long-term condition e.g. diabetes, arthritis	A 92 year old should not be expected to make their own way to specialist clinics
Long-term condition e.g. diabetes, arthritis	Consultant unhelpful and rude. I ended up going private.
Long-term condition e.g. diabetes, arthritis	No care offered once specialist letter went to GP . This was over 20 years ago. My wife managed to get me some neurological physio therapy but this was only for 2 months. It’s needed for life to help with balance and coordination so I took up Pilates. But the condition deteriorates over time but at an unknown rate so can’t predict what help I will need when. May need a wheelchair eventually, may not. Im not monitored for deterioration by my GP
Long-term condition e.g. diabetes, arthritis	No support was given as there was no support in our area that dealt with epilepsy
Long-term condition e.g. diabetes, arthritis	Things are not properly explained and there is a lack of services for certain conditions.
Long-term condition e.g. diabetes, arthritis	There are no ME specialists. It's a dustbin diagnosis.
Long-term condition e.g. diabetes, arthritis	Up had to come to rescue and chase things up and try and sort misunderstandings and lack of medical notes

Long-term condition e.g. diabetes, arthritis	There was poor communication between the person doing the tests and the doctor
Long-term condition e.g. diabetes, arthritis	No help with mental Health care regarding the diagnosis
Long-term condition e.g. diabetes, arthritis	The treatment the individual receives is vey much based on clinical need i.e. treating their condition. There does not appear to be any consideration of (and therefore support for) of how their eye condition impacts their lifestyle, mental health etc.
Long-term condition e.g. diabetes, arthritis	It did not continue for long enough.
Long-term condition e.g. diabetes, arthritis	Sometimes I wonder if they are making it up as they go along!! There have been times with some treatment I felt it was common sense or its a question of this way gets them off the list. I go along with some things because if you don't you are liable to be sent back to the beginning or completely discharged!!!
Long-term condition e.g. diabetes, arthritis	It was a lengthy amount of time between initial appointment and seeing the specialist
Long-term condition e.g. diabetes, arthritis	Good, caring and helpful support from specialist nurse/technician. This reduced by half in subsequent years.
Long-term condition e.g. diabetes, arthritis	Information on support services / groups would have been useful.
Long-term condition e.g. diabetes, arthritis	Expectations were met until we lost 1 of our Parkinson’s nurses , this needs rectification.
Long-term condition e.g. diabetes, arthritis	Was not given the information after seeing the specialist, now have the information waiting to hear back.
Long-term condition e.g. diabetes, arthritis	Expectations were met until we lost 1 of our Parkinson’s nurses , this needs rectification.
Long-term condition e.g. diabetes, arthritis	I was signposted to have an X-ray then the Consultant I went to wasn’t his specialty the following week I was seen by the appropriate consultant who has been fantastic supportive and quick acting. First class why couldn’t I get that treatment from the start.
Long-term condition e.g. diabetes, arthritis	My eye condition was and is still monitored with annual eye hospital visits
Long-term condition e.g. diabetes, arthritis	I didn’t have expectations

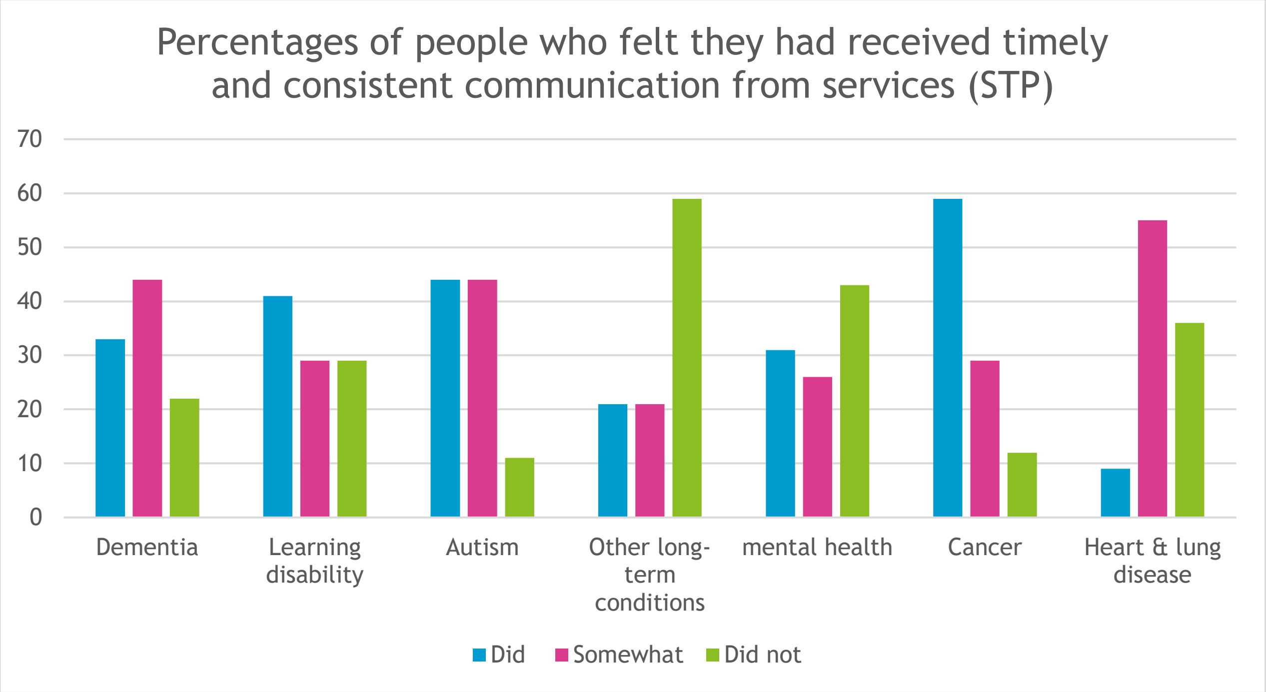
Long-term condition e.g. diabetes, arthritis	Not given any options
Long-term condition e.g. diabetes, arthritis	There is no further care for stroke victims
Long-term condition e.g. diabetes, arthritis	I got passed back to GP care who refused to do anything. If it wasn't for a metabolic support charity I wouldn't be where I am today
Long-term condition e.g. diabetes, arthritis	Listening to what I was saying and understanding my concerns
Long-term condition e.g. diabetes, arthritis	It’s timely and a place I can get to without paying parking
Long-term condition e.g. diabetes, arthritis	Experience with nurses is better than the doctors because they have more time (at one GP practice) Follow up appointment reminders are good.
Long-term condition e.g. diabetes, arthritis	Not at all
Mental health	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
Mental health	My anxiety stopped me leaving the house, but the doctor told me I just had to learn to live with it and essentially told me to get over it.
Mental health	Had CBT-I help from a great lady
Mental health	Offered general CBT telephone appt during working hours.
Mental health	My psychologist is very highly trained in my condition so knows what she is on about and is able to give me the correct help
Mental health	I don't need to explain it. But I always have care support
Mental health	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. Who can direct services to each provision - an organisation like IASS who are 'for the people' who listen impartially, understand your needs and direct you to the place they understand you need to go. A central place who is separately funded who are not in the hands of big pharmaceutical companies.
Mental health	Had to find out by myself what options they were and how to access them. Still not sure I know if all if them yet
Mental health	discharged early because of lack of beds, care coordinator on holiday with no coverage, no support, actually no contact< when primary carer was rushed into hospital.

Mental health	wished to have quicker response because feeling panicky
Mental health	You get lost in the system
Mental health	Aftercare at the Hospital was as variable as the different departments (and I have used a lot of them). When I could receive aftercare, eg removal of stitches at my local medical practice, the service was much more personal and appropriate.
Mental health	I was only offered medication for my anxiety which has made things a lot worse for me
Mental health	I was only offered medication for my anxiety which has made things a lot worse for me
Mental health	Over the phone consultations through Skype on I phone did not go well as my child would not participate
Mental health	I was told to contact crises team but I do not fit their criteria at this time. Both GP surgery and social worker said go to crises team.
Mental health	Face to face contact with a specialist
Mental health	Gave me the tools to self manage
Mental health	Once signed off, have to go through waiting list again. No follow up or additional support.

19a. During your whole experience of getting support did you receive timeline and consistent communication from all of the services that you came into contact with?

During your whole experience of getting support did you receive timely and consistent communication from all of the services that you came into contact with?

	Shropshire	Telford & Wrekin	Grand Total
No	30	33	63
Somewhat	20	25	45
Yes	21	27	48
Blank	6	3	9
Grand Total	**77**	**88**	**165**



19b Please explain how the care did or did not meet your expectations and how it could have been improved. [free text]

Autism	Dad help me
Autism	I was given info on local support of services we could access.
Autism	Once diagnosed have had regular appointments with CAMHS and a lot of helpful information
Autism	There was no support from the NHS. We found support elsewhere.
Autism	Sometimes the consistency was not there and I would have to chase and follow up a lot. Messages not being passed on and appointments not being set up was a little frustrating.
Autism	It was better than i expected. Very helpful. Brilliant.
Cancer	Counselling was hard to obtain but the other services were great.
Cancer	Everyone very good at their job but sometimes empathy was lacking
Cancer	As above
Cancer	alot of information was repeated alot of advice offered was the same as the previous professional - all rather standard answers! if you have tried it and it doesn't work for you it's bit frustrating.
Cancer	People did what they said they would do without delay - this was essential
Cancer	Only improvement in my case would be more local to where I live

Cancer	Care by (GP practice removed) was excellent. I believe care companys can only provide the care required if they are given all requirements of receipts.
Cancer	Long waiting time in clinics could be improved, but generally caused by not enough staff for the amount of patients.
Dementia	Lack of Resources to meet the needs of Carers. Seems more Scarce resources are all aimed at Reducing Bed Blocking and not enough Priority to preventive work in supporting Carers in the Community to minimise hospital admissions. Many Carers Suffer greatly with lack of support
Dementia	Very infrequent, left to get on with it.
Dementia	More information available to family as a whole - carers centre was an important support to us
Dementia	Supporting our family and mum in residential care
Heart and lung diseases	Not given any support at all.
Heart and lung diseases	Following initial doctor appointment i didn't expect to have to wait a year for an operation. I also hoped to get more help with arthritis.
Heart and lung diseases	Delays in prognosis and proposed treatments
Heart and lung diseases	Difficulty getting details for some of the treatment especially the cardio-version, he was discharged too soon after this procedure. He was very disorientated.
Heart and lung diseases	Can't answer this question, given the multiple services involved and timescale
Heart and lung diseases	Shrewsbury communication nonexistent
Heart and lung diseases	Understanding and they listened which was all I needed
Learning disability	Okay
Learning disability	I am ok because of good doctors and nurses
Learning disability	Too long waiting between appointments
Learning disability	Happy
Learning disability	Time table was set up. I could call, text and video chat
Long-term condition e.g. diabetes, arthritis	Still waiting
Long-term condition e.g. diabetes, arthritis	Please look at the whole person & stop being influenced by pharmaceutical companies

Long-term condition e.g. diabetes, arthritis	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 - if they do. In fact I don't actually know what a care plan is supposed to be. I think there needs to be some central place where all the information is accessible to me so I know what is being communicated between the various departments involved and whether or not this information is accurate. My file is very big so I know that in the short time that doctors and nurses have available to see me it is unlikely that they have read that much about my case. This coupled with the general ignorance about ME/CFS means that it is unlikely that they necessarily have much understanding of what I am telling them without me being able to give them some greater insight. If I knew what was in my file I would be able to prepare a more specific set of questions and information to bring to a consultation saving everyone time (and possibly expense) by being more focused on what the doctor/nurse needs to know from me.
Long-term condition e.g. diabetes, arthritis	As above. A the time our expectation were exceeded
Long-term condition e.g. diabetes, arthritis	GP/counsellor. No other support.
Long-term condition e.g. diabetes, arthritis	Quicker responses and not having to keeping chasing appointments
Long-term condition e.g. diabetes, arthritis	as above made to feel like wasting time if wanted a conversation with GP. Even though until diagnosed with heart problems, never visited GP
Long-term condition e.g. diabetes, arthritis	Communications has been sent to a previous address which resulted in missed appointments and rearranging these appt has meant a 6 month wait to see an epilepsy nurse, when my partner has concerns. records at the doctors were not updated.
Long-term condition e.g. diabetes, arthritis	Letter not received or received after appointment
Long-term condition e.g. diabetes, arthritis	No information available as there is no treatment and no cure. Also far too little research funding going into it, it’s reliant on charities like Ataxia UK to fund it. Everyone focuses on cancer like it’s the only thing that affects people.
Long-term condition e.g. diabetes, arthritis	Some of the write ups are missing huge amounts of information including symptoms which explains why nobody can diagnose anything. GPS are trying to treat ONE symptom rather than looking at symptoms and linking them.
Long-term condition e.g. diabetes, arthritis	Not quick enough and not delivered by people who understand ME.
Long-term condition e.g. diabetes, arthritis	I needed medical records from another hospital and they did not send for years and what they did was not correct or missing

Long-term condition e.g. diabetes, arthritis	I was not given any suggestions on relieving the painful symptoms
Long-term condition e.g. diabetes, arthritis	Ongoing delays between treatments - injections very rarely take place within the timescales recommended by the Consultant / Specialist Nurse.
Long-term condition e.g. diabetes, arthritis	I was on a course of daily injections for two years. It was my G P who contacted the consultant again.
Long-term condition e.g. diabetes, arthritis	Chasing up my own results and don't get me started on the RA dept at Telford and Wrekin.
Long-term condition e.g. diabetes, arthritis	Discovered by accident that service location and support model had changed when ringing the support number given and told no longer at that hospital. Was also not sent follow up or review appointments on two occasions.
Long-term condition e.g. diabetes, arthritis	What is timeline?
Long-term condition e.g. diabetes, arthritis	Always copied into neurologist reports, never copied into gastrology reports. The nurses from both departments are very good, but under pressure.
Long-term condition e.g. diabetes, arthritis	As above.
Long-term condition e.g. diabetes, arthritis	Always copied into neurologist reports, never copied into gastrology reports. The nurses from both departments are very good, but under pressure.
Long-term condition e.g. diabetes, arthritis	I was seen by the Consultant sent to pre op then MRI scan next day then admitted to hospital top toe joint removed he has been excellent actually outstanding. I feel safe Andrea,ky happy with the care and support from his team.
Long-term condition e.g. diabetes, arthritis	Appointments have continued to be offered.
Long-term condition e.g. diabetes, arthritis	Diabetes support 1 months meeting was excellent
Long-term condition e.g. diabetes, arthritis	Telford and Shrewsbury hospitals tell the patient and family nothing at all unless you happen to be a patient who is a doctor
Long-term condition e.g. diabetes, arthritis	You get told the referral is done, receive a confirmation letter and nothing else until there is an appointment available As previously stated this was 9 months after the referral and I had no communication during waiting process.

Long-term condition e.g. diabetes, arthritis	Getting to the services sometimes difficult, childcare was a problem long waiting times a bit of an issue with a small child
Long-term condition e.g. diabetes, arthritis	Saw the same person each time
Long-term condition e.g. diabetes, arthritis	In the last 12 weeks I have seen more than 5 specialists who consistently change their minds
Mental health	My GP has told me that in their view everyone on their patient list would benefit from a course of CBT so I felt lucky to have had the chance to work with a member of staff at IAPT to learn and work through things using the tools of CBT.
Mental health	Like I said above I've not been seen yet
Mental health	Dating 3 weeks for doctor appointment and then seeing a different doctor everytime
Mental health	Confirmed details by letter.
Mental health	I had telephone support while I waited for the help
Mental health	I don't need to explain it because I always have care support
Mental health	Irs hard to get any information out of them
Mental health	basically treated like mushrooms, kept in the dark and fed on sh*t
Mental health	It's been nearly a year that I've been waiting to speak to a counselor
Mental health	Not long enough appointments
Mental health	Diagnostic results are taking longer and longer to arrive, and I have to continuously phone my GP until they arrive, if at all. They dont phone or contact me in any way. I have come across younger and under-trained nurses and care assistants, who can sometimes be quite insensitive. Older staff are almost always easier to talk to and to be cared for by. My District General Hospital, from which I have always received excellent treatment, is the Royal Shrewsbury Hospital, which has problems of its own. I don't blame them for their shortcomings in communications.
Mental health	Having still got severe anxiety, the mental health practitioner I am assigned to doesn't seem to reply to my emergencies. There needs to be more communication.
Mental health	Having still got severe anxiety, the mental health practitioner I am assigned to doesn't seem to reply to my emergencies. There needs to be more communication.
Mental health	It helped me talk to consultants but did not help my child
Mental health	GP surgery at Limes walk Oakengates need to be more accessible by phone. More GP appointments need to be available.

Mental health	It could have been like it was a few years ago where a support worker (mental health nurse) came out to her.
Mental health	Very good , improved my health and management of my conditions
Mental health	Once seeing therapist a course of treatment which should have been 20 weeks took over a year to complete due to constant cancellation of appointments.

Time spent travelling to access support and care

20. What is your main means of transport?

What is your main means of transport?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Own car	46	57	103
Another person's car	20	15	35
Bus	5	8	13
Train		1	1
Taxi	2	2	4
Other	4	3	7
Blank		2	2
Grand Total	**77**	**88**	**165**

21. How much time would you be willing to travel for to receive a quick and accurate diagnosis?

How much time would you be willing to travel for to receive a quick and accurate diagnosis?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Less than 30 minutes	16	21	37
30 minutes to 1 hour	33	41	74
1 - 2 hours	16	14	30
Over 2 hours	11	7	18
Blank	1	5	6
Grand Total	**77**	**88**	**165**

22. How much time would you be willing to travel for to receive specialist treatment or support?

How much time would you be willing to travel to receive specialist treatment or support?			
	Shropshire	Telford & Wrekin	Grand Total
Less than 30 minutes	9	19	28
30 minutes to 1 hour	35	35	70
1-2 hours	16	23	39
More than 2 hours	16	9	25
Blank	1	2	3
Grand Total	**77**	**88**	**165**

Your expectations at each stage of your care

23. What is most important you?

When first seeking help			
	Shropshire	Telford & Wrekin	Grand Total
Seeing a health professional you normally see but you may have to wait	28	28	56
Seeing any medically appropriate health professional who is free immediately	26	38	64
Don’t mind	10	13	23
Blank	13	9	22
Grand Total	**77**	**88**	**165**

When you received a diagnosis and explanation of treatment or support options			
	Shropshire	Telford & Wrekin	Grand Total
Seeing a health professional you normally see but you may have to wait	34	29	63
Seeing any medically appropriate health professional who is free immediately	25	39	64
Don’t mind	5	8	13
Blank	13	12	25

Grand Total	**77**	**88**	**165**

During your initial treatment or support			
	Shropshire	Telford & Wrekin	Grand Total
Seeing a health professional you normally see but you may have to wait	30	31	61
Seeing any medically appropriate health professional who is free immediately	29	40	69
Don't mind	4	7	11
Blank	14	10	24
Grand Total	**77**	**88**	**165**

During your long term support			
	Shropshire	Telford & Wrekin	Grand Total
Seeing a health professional you normally see but you may have to wait	44	32	76
Seeing any medically appropriate health professional who is free immediately	16	34	50
Don't mind	5	10	15
Blank	12	12	24
Grand Total	**77**	**88**	**165**

Supporting you to have more control over your own care

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

What level of support do you want the NHS to provide to help you stay healthy?			
	Shropshire	Telford & Wrekin	Grand Total
A lot of support	20	30	50
Some support	49	43	92
I don't need support	5	6	11
Don't know	3	3	6

Blank		6	6
Grand Total	**77**	**88**	**165**

25. What could the NHS do to help you stay healthy or manage any condition you have? [free text]

Autism	Help my dad and my day service
Autism	More support for parents and children with special needs. Maybe groups of parents with children who have similar needs.
Autism	Cut waiting times.childrens mental health in Telford is appalling, South Staffordshire should be removed. Insufficient staff and pressure to discharge regardless of the patients best interest. PALS just as useless - no response from a formal complaint
Autism	Provide more after care and support after diagnosis also provide staff training with autism and learning difficulties as when my son went to A and E it was difficult and understanding staff with different techniques to handle this would be great
Autism	Continued help from SALT. Learning help about dangers, road safety. Maybe workshops for carers/parents. Expert help on foods with sensory issues. Help with moving to ground floor properties, rather than trying to adjust a house that could be dangerous for the autistic child who cannot do stairs and recognise danger, and likes windows. Sometimes a move in home is better/safer. So , help with moving, even writing a letter to help a move.
Cancer	I worry I am going to be a burden when my mental health issues flare up and knowing there is a huge waiting list for counselling so try and cope at home. I worry that I will end up in an institution when issues flare up and I feel I cannot cope. The mental health services are overstretched and due to that many patients feel that they will not get treatment they require so give up seeking help.
Cancer	Possibly sort out the abrubt end. "You have finished that now. See you in 6 months" . Don't mean keep seeing you but a reassuring this may happen,. Or this. Feel free to contact us if you have any concern/worries. Or ask to speak to you GP. Ut felt a bit like ok off you go now. We have other people to see. You're done. Hope everything goes well but dont botter us
Cancer	With most cancers there is not s way to stay healthy. Terminal cancer sufferers and their families are left to cope with it all
Cancer	regular reviews, a care plan would be good so know what to do and expect. Never had one in cancer care
Cancer	Advice and guidance, reliable information in different formats, access to health professionals when needed but not necessarily a doctor
Cancer	Local support
Cancer	Provide access to guided exercise and/or physiotherapy.

Cancer	My medical practise looks after my health fairly well and my only "beef" is difficulty getting an appointment to see preferred doctor.
Cancer	Give clinical nurses a slot in their day to speak to patients. ..just to check how they and their wife partner are doing!!!
Cancer	Give clinical nurses a slot in their day to speak to patients. ..just to check how they and their wife partner are doing!!!
Cancer	Make access to GP easier & be able to see the same GP.
Dementia	AS Mum was over 90 with Dementia .It would have been nice to have received a home visit . In the 6 years we looked after Mum . We only received one unannounced Doctors Visit
Dementia	Yes if adequate support give in home and to cares.
Dementia	Advice and guidance around a number of areas - Dementia, Diet
Dementia	Provide information and appropriate signposting.
Dementia	Provide free profession care for Alzheimer's patients.
Dementia	Provide free profession care for Alzheimer's patients.
Heart and lung diseases	Offer timely expertise.
Heart and lung diseases	I didn't want to be dismissed and made to feel like a time waster.
Heart and lung diseases	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.
Heart and lung diseases	This condition needs a lot of drug management, and monitoring. I have had to have many investigations and complex interventions like stents.
Heart and lung diseases	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.
Heart and lung diseases	Listen and see me as a whole person
Learning disability	I get support from my sister
Learning disability	Workshops and things at our Service (day). That used to happen they don't happen anymore. Like fitness / gym. Lots of things have stopped. I like the Wise up shape up Days (Taking Part & RCC used to do)
Learning disability	not sure
Learning disability	PROVIDE MORE TRAINING FOR PUBLIC TO STAY HEALTHY. GET COMPANIES TO MAKE HEALTHY OPTIONS

Learning disability	Not sure
Learning disability	Keep checking up on me. Make sure I am ok
Learning disability	More specialist advice
Learning disability	Have more people who can communicate in different ways
Learning disability	Staff deal with it. My condition is managed
Long-term condition e.g. diabetes, arthritis	Provide more specialists in Shropshire for specialist conditions. An autism specialist would be great. A fibromyalgia specialist...not a rheumatologist or neurologist who diagnose and then discharge you. The ME debate is huge in government...these patients suffer horrendously so an ME specialist would be good. Pain management solutions need to provide programmes longer than 1 hour for 6 weeks. Funded exercise classes that help you with fibromyalgia
Long-term condition e.g. diabetes, arthritis	Learn about optimal human nutrition
Long-term condition e.g. diabetes, arthritis	Have a specialist Clinic for ME/CFS and similar conditions
Long-term condition e.g. diabetes, arthritis	Education on long term conditions and impact on families.
Long-term condition e.g. diabetes, arthritis	Support the use of continuous glucose monitoring which I am currently funding myself at considerable expense.
Long-term condition e.g. diabetes, arthritis	Allocate more nurses and equipment to a renal unit
Long-term condition e.g. diabetes, arthritis	Fund our NHS professionally using the medical knowledge available.
Long-term condition e.g. diabetes, arthritis	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
Long-term condition e.g. diabetes, arthritis	Listen to my concerns and have a programme of planned care instead of keep starting over andover again
Long-term condition e.g. diabetes, arthritis	To save time, could you have option to send in questions to GP before consultation. So GP is prepared for visit
Long-term condition e.g. diabetes, arthritis	Undertake regular check up / scans to monitor changes and provide me with accurate current picture to help me decide how to manage my condition

Long-term condition e.g. diabetes, arthritis	A different drug, options are running out
Long-term condition e.g. diabetes, arthritis	have more clinics available at my local GP Practice or utilise Community centres if space id a problem
Long-term condition e.g. diabetes, arthritis	Assist with controlling my diet and weight loss. Monitoring of general health within long term conditions e.g. weight, BP, blood sugar, cardiac and stroke prevention advice and monitoring.
Long-term condition e.g. diabetes, arthritis	Gp great when really need it
Long-term condition e.g. diabetes, arthritis	Listen better to symptoms and advise you at the time of pain.
Long-term condition e.g. diabetes, arthritis	Pay for Pilates classes or provide physiotherapy. Fund travel to the London specialist centre from Shropshire
Long-term condition e.g. diabetes, arthritis	I think it would be good if there was a name of charities or businesses who may be of use to myself / my family.
Long-term condition e.g. diabetes, arthritis	They could offer laser treatment for excess hair, at the moment it’s only available for men who want to be women and not for women who have conditions. There could be more ongoing support to help with mobility for younger people with debilitating conditions. Animal therapy could be introduced to help with depression.
Long-term condition e.g. diabetes, arthritis	Believe that ME is a physical illness. Provide peer support. Invest money in finding out how life with ME can be improved.
Long-term condition e.g. diabetes, arthritis	More test to be diagnosed not just have DOB looked at
Long-term condition e.g. diabetes, arthritis	Keep my records up to date reviews treatments when meant to for conditions.
Long-term condition e.g. diabetes, arthritis	Give suggestion that may help short/long term
Long-term condition e.g. diabetes, arthritis	Being able to contact someone to ask for advice regarding daughters diabetes at all times (within reason)
Long-term condition e.g. diabetes, arthritis	Better co-ordination of support for people with multiple conditions rather than treating each condition in isolation.

Long-term condition e.g. diabetes, arthritis	Easier access to the GP of my choice
Long-term condition e.g. diabetes, arthritis	Regular check ups even help at the end of a telephone if you need it.
Long-term condition e.g. diabetes, arthritis	answers to above questions of who and how fast to access all depend upon what the suspected problem is. Suspected heart attack will have different answers to travel advice. Provision of supported self care for long-term conditions and access to community resources to prevent onset of dread diseases like diabetes, dementia, stroke, cancer.
Long-term condition e.g. diabetes, arthritis	Quick and easy access when unwell.
Long-term condition e.g. diabetes, arthritis	Replace the missing Parkinson's nurse, Sorry to keep going on but he left of his own accord not cutbacks.
Long-term condition e.g. diabetes, arthritis	Actually giving me the information and support in the first place.
Long-term condition e.g. diabetes, arthritis	Replace the missing Parkinson's nurse, Sorry to keep going on but he left of his own accord not cutbacks.
Long-term condition e.g. diabetes, arthritis	Timely checks on long term conditions
Long-term condition e.g. diabetes, arthritis	This is difficult to ascertain as it depends on how the condition changes
Long-term condition e.g. diabetes, arthritis	A cess to appropriate excercise and equipment and adaptions for Parkinsons
Long-term condition e.g. diabetes, arthritis	regular checks
Long-term condition e.g. diabetes, arthritis	I think this is an unfair question for my condition, i have something which is unpreventable. The NHS have done their best with me with the pressure they are facing. I think the NHS needs to priorities the health care professionals health.
Long-term condition e.g. diabetes, arthritis	Have someone at hand for advice and help andvtgst actually cares
Long-term condition e.g. diabetes, arthritis	My condition I was diagnosed with is not recognised by the NHS I find myself explaining to relevant professionals what it is when I have no information myself, once I seen the genetic specliast I find out that I don't have that condition and

	pot8a connective tissue disorder. I have to travel by train to Birmingham hospital to be seen.
Long-term condition e.g. diabetes, arthritis	As it's difficult to get it's best I do it myself
Long-term condition e.g. diabetes, arthritis	Be there when I need it
Long-term condition e.g. diabetes, arthritis	Provide more after care/rehabilitation. ! hour a week for 6 weeks after leaving hospital is a disgrace and hopeless.
Long-term condition e.g. diabetes, arthritis	Because I have medication each month it can be costly - perhaps medication could/should be more individualised
Long-term condition e.g. diabetes, arthritis	Communicate with each other
Mental health	Clear information and advice that goes into the right amount of detail for the individual. I think the internet is a huge problem as there is quite a lot of contradictory information out there. I am a bright and articulate person so guidance on what information to read at a level and depth suitable to me would be helpful.
Mental health	Not have to wait so long for Drs appointments, takes so long to get one often put going to drs till I really need to go
Mental health	Regular three or four months check up just to make sure all is well, so not to relapse.
Mental health	Am not sure
Mental health	By losing weight and I have heart and thyroid condition
Mental health	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
Mental health	Regular health checks
Mental health	better information and drop in points
Mental health	Unsure. I feel the NHS does a lot under pressure for sure
Mental health	More support, feel like your listened too
Mental health	Get adequate funding for ancillary services such as public transport and local leisure services, so that we are not under endless threats of cuts, reductions and outsourcing. Make sure that local pharmacies are kept open, how else to get the maintenance medication we need? I would have to travel 20 miles to the next nearest, and buses are about to be cut.

Mental health	Bringing sessions into college for students
Mental health	Link more with GPs, support groups and social services so a holistic package can be given to enable someone to live a healthy home like in their own home.
Mental health	Face to face contact with a specialist. Possibly cognitive behavioural therapy.
Mental health	No more than what I am getting generally, however quicker access to CBT would be beneficial if required
Mental health	See a the same practitioner who is familiar with my progress.

26. If you have any further comments please write them below [free text]

Autism	Support for teens with autism, particular girls seems lacking.
Cancer	Cancer services have improved greatly since I was diagnosed many years ago. Dignity and respect really need to be taken into consideration when people attend for scans for breast cancer at Royal Shrewsbury Hospital and please discard those lilac striped shawls as an "expert patient" I would prefer to bring an old t-shirt for a scan. This would save the hospital on laundry costs.
Cancer	Cannot fault the timing etc. After care very poor
Cancer	Gp practices need to be more involved. Once the diagnosis is received it is highly unlikely that you will receive or get any further care from them. In birmingham you so not even get a call asking how you or their patient is. In highley where I live the gp surgerybus quite small but they put most gp surgeries to shame
Cancer	I personally have medical problems of my own but I am pleased to say that PRH Audio Dept has been excellent and (GP NAME REMOVED) did an excellent job replacing my knee.
Dementia	n/a
Dementia	Alzheimer's patient are discriminated against as they do not receive care from the NHS as everyone else who is ill does. They are totally relient on friends and family if they are lucky. They are the most VUNERABLE in society as they can't manage their own illness. They are incapable of making informed decisions and do not understand what is happen ending to them. It is the only illness to my knowledge that the NHS does not provide care for. These patients are left to buy private care and are discriminated against by doing so. They are not treated equally to the rest of society. I believe this is so because the NHS knows they cannot stand up for themselves and therefore are ignored.
Dementia	Alzheimer's patient are discriminated against as they do not receive care from the NHS as everyone else who is ill does. They are totally relient on friends and family if they are lucky. They are the most VUNERABLE in society as they can't manage their own illness. They are incapable of making informed decisions and do not understand what is happen ending to them. It is the only illness to my knowledge that the NHS does not provide care for. These patients are left to buy private care and are discriminated against by doing so. They are not treated equally to the rest of society. I believe this is so because the NHS knows they cannot stand up for themselves and therefore are ignored.

Heart and lung diseases	I don't blame the doctor or physio but something has to change.
Heart and lung diseases	Although my consultant has been seen through private medical insurance route I have also needed a lot of help from my GP.
Heart and lung diseases	I have congenital heart disease and restrictive respiratory condition
Learning disability	No
Learning disability	More than happy with all my care and where I live
Long-term condition e.g. diabetes, arthritis	Please raise the profile of autism, fibromyalgia, ME and injury from mesh whether that be for hernia repair or for pelvic problems. 4 conditions derated time to address them all properly.
Long-term condition e.g. diabetes, arthritis	I am very grateful to the NHS in Shropshire for the support they have and do give me within the limitations that they are working under given the lack of research into my particular condition and the misdirection given by the psychiatric profession and the inadequate NICE guidelines but would dearly love to have somewhere and some people who really understand how to deal with the condition and who are at the cutting edge of what can be done to treat and support people who have to live with this debilitating disease.
Long-term condition e.g. diabetes, arthritis	ME/CFS has had hardly any help or support. I was fortunate to have a GP, family and friends who understoood I was genuinely ill, and could not do GET. I do exercise, but need to be very careful when and how. I know and speak to many people with it as take the phone calls for Shropshire ME Group. Research is urgently needed, specialists and nurses to diagnose and support, and GET stopped now - rather than waiting for the new NHS guidelines. I have got much better with Dr. Myhill, due to T3 tests etc etc. Allow other GPs to think outside of the box!
Long-term condition e.g. diabetes, arthritis	AT current GP surgery. Constant Locom GPs , cant seem to keep staff. A real concern not enough GPs & Nurses in NHS Nurses should go back to being trained on the job not sent to do a degree!
Long-term condition e.g. diabetes, arthritis	My Gp surely is great our Aand E is too shame they are closing it down.
Long-term condition e.g. diabetes, arthritis	It would be good if consultants did not make rude remarks or try and blame weight when they haven't read facts. Learn about conditions that may me different like cvi sight loss they stroke etc
Long-term condition e.g. diabetes, arthritis	I have completed this form on behalf of someone whose primary care need is visual impairment but is also frail elderly, hearing impaired, has poor balance and mobility, a lung condition and memory problems. At present, their support seems to consist of 10 minute appointments with their GP (if they can get an appointment) meaning they need to prioritise which of their conditions is giving them most trouble at the time. If they are referred to specialist services, those only seem to focus on the condition for which they are referred. In reality, it is the combined effects of all their conditions which impacts on the quality of their daily life.

Long-term condition e.g. diabetes, arthritis	As I am over 80 I would like easier access to a known GP or support system.
Long-term condition e.g. diabetes, arthritis	Make sure the NHS collects all the money owing to them from foreigners but my guess is that will never happen!!!! Make sure people have paid their contributions to the NHS BEFORE you treat them and make sure foreigners have health insurance before treatment. Alright give them first aid but make sure they can pay just the same as happens to us when we are abroad.
Long-term condition e.g. diabetes, arthritis	All this pre-supposes contact with the NHS in first place. My view is that health is not only repairing diseases once diagnosed, but positive wellbeing and prevention of disease.
Long-term condition e.g. diabetes, arthritis	Please can patients with complex long term conditions be seen by one person so they g et to now the person and are quick to notice changes.
Long-term condition e.g. diabetes, arthritis	Shropshire must be the worst authority for lack of communication and care. Compared to neighbouring Worcester they leave a lot to be desired
Long-term condition e.g. diabetes, arthritis	This is about myself. I've also had difficulty with my sons mental health. Bee-U refused further assessment but happily accepted a private self funded report to potientally give me some idea how to help my son. Its been 7 years fighting to get my son help, my own physical health and mental health being blamed for my son. My conditions are believed to have been triggered by stress.
Long-term condition e.g. diabetes, arthritis	It would be good if you could see the same clinician each time you need advice in one of your conditions flares up as they know you then things wouldn't get missed.
Long-term condition e.g. diabetes, arthritis	We have been shocked and horrified with the level of support for rehabilitation after my partner leaves the hospital. I hour a week for 6 weeks is not acceptable for people living with a catastrophic life changing injury! My partner was due to be discharged on the 20th of February but her still remains in hospital while we are sorting out home adaptations. He walked last Friday for the first time in 6 months! This would not have been achieved had he left hospital on the discharge date! This has proved that there must be people out there in Local Authority care, with the potential to recover better use of their body but due to funding there are subjected to a second rate life style! Disgusting!
Mental health	During my time of severe anxiety I was placed on antidepressants that were making it worse, the GP did not pick up on this until a year and a half later when I changed doctors. Despite my need for actual help I was not offered any and so watched as my mental health shrunk my life to the size of my house. I needed real help and the NHS wrote me off completely. If it were not for the support of my family I would have been in terrible trouble.
Mental health	The section for "Your expectations at each stage of your care" does not allow you to scroll right on a mobile!
Mental health	Long term support with mental health should be available to all. Stop focusing on the current trendy problem, and start looking after everyone.

Mental health	All these things are interconnected. We need: local leisure facilities and clean accessible and safe open spaces for exercise; local pharmacies for advice and medication; general practices with enough staff and modern communications; an ambulance service in case of emergencies, that is not held up by long waits at A&E; stop threatening to close A&E and trauma centres; adequate state-funded "step-down" and social care facilities, so that people can get home and not "block beds"; "good neighbour" organisations in the community to enable older and disabled people to stay at home; befriending organisations to help prevent loneliness and isolation,; good public transport - and back to the beginning again!
Mental health	Not diagnosed or assessed due to son with mental health issues not consentry to a 3 hour assessment, which would give him anxiety. Accessing support could have been improved - talking to professionals about a child , this should not be done in front of a child as it makes things worse for a child.
Mental health	GPs need to refer people to the available support groups can offer in the community.
Mental health	The patient lives in a remote location, does not drive and there is no bus service. Her son lives away, so she is reliant on extended family members for lifts.
Mental health	This survey form became confusing once the question regarding more than one condition had been answered

Tell us a bit about you

By telling us more information about yourself, you will help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

27. Your age

Your age			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Under 18		5	5
18-24	5	3	8
25-34	9	11	20
35-44	10	10	20
45-54	13	26	39
55-64	20	12	32
65-74	10	13	23
75+	9	7	16
Blank	1	1	2
Grand Total	**77**	**88**	**165**

28. *Your ethnicity*

Your ethnicity			
	Shropshire	**Telford & Wrekin**	**Grand Total**
African		1	1
Any other white background		1	1
Arab	1		1
Asian British		1	1
Bangladeshi		1	1
Pakistani		2	2
White British	74	79	153
Black British		1	1
Blank	2	2	4
Grand Total	**77**	**88**	**165**

29. *Do you consider yourself to have a disability?*

Do you consider yourself to have a disability?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Yes	37	39	76
No	34	45	79
I'd prefer not to say	5	3	8
Blank	1	1	2
Grand Total	**77**	**88**	**165**

30. *Are you a carer?*

Are you a carer?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Yes	14	30	44
No	61	57	118
Blank	2	1	3

Grand Total	**77**	**88**	**165**

31. Which of the following best describes you?

Which of the following best describes you?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Bisexual	1		1
Gay or lesbian	1	5	6
Heterosexual	63	70	133
I'd prefer not to say	7	6	13
Other	4	4	8
Blank	1	3	4
Grand Total	**77**	**88**	**165**

32. Your gender

What gender do you identify as?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Male	22	26	48
Female	51	60	111
I'd prefer not to say	1	1	2
Blank	3	1	4
Grand Total	**77**	**88**	**165**

33. Your religion

Which, if any best describes your religious beliefs?			
	Shropshire	**Telford & Wrekin**	**Grand Total**
Muslim	1	2	3
Christian	36	44	80
Jewish	1		1
Other	3	7	10
No religion	30	26	56

I'd prefer not to say	5	8	13
Blank	1	1	2
Grand Total	**77**	**88**	**165**

Count of themes

Count of themes raised in feedback to questions 6b, 13, 14, 18b, 19b, 25, 26

Themes	Mental Health	LTC	Learning Disability	Heart & Lung	Dementia	Cancer	Autism	Grand Total
Access to specialist services	5	11		1		4	3	24
Information & Advice	4	7	4	1	2	2	4	24
Communication with patient	3	10	4	3		1		21
Listen to me	2	13				1	1	17
Continuity of staff	3	9				1		13
Communication between staff/services	3	6				1	2	12
Condition review/monitoring	3	6		1		1		11
GP Access	2	3		1		2		8
Support In the community	3	3					1	7
Staff training	2	3				1	1	7
Signposting		2	1		1	1	1	6
Exercise support	1	3	1					5
Psychological support	1	3				1		5
Co-ordination of services	2	2						4
Support for carers	1				2			3
Access to services outside 'office hours'	3							3
Peer group support		1					1	2
Dietary assistance	1	1						2
Personalisation	1	1						2
Holistic approach to person not condition		1		1				2

Ongoing support		1					1	2
Lifestyle		1	1					2
Support to self-manage	1							1
Autism awareness		1						1
Physiotherapy		1						1
Public transport	1							1
Equipment		1						1
See me not my condition		1						1
Treatment choices							1	1
Medical records		1						1
Community based rehabilitation		1						1
Condition Awareness							1	1
Grand Total	**42**	**93**	**11**	**8**	**5**	**16**	**17**	**192**

Appendix 3: Dementia Focus Group Feedback

Summary

Healthwatch Shropshire attended ten groups and Healthwatch Telford & Wrekin attended 6 groups. These took place in various locations and setting around Shropshire, Telford & Wrekin. The groups included both those living with dementia and their carers.

Focus Group Summaries:

Shropshire

S1) 02/04/19 Alzheimer's Peer Support Group, Shrewsbury - carers 9

S2) 02/04/19 Dementia Football Highley - carers 3, living with dementia 4

S3) 03/04/19 Alzheimer's Dementia Café Ludlow - carers 6, people living with dementia 5

S4) 10/04/19 Market Drayton Festival of Wellbeing - carers 1, people living with dementia 3

S5) 12/04/19 Alzheimer's Peer Support Group, Church Stretton - carers 3

S6) 16/04/19 RCC Care & Share Group - carers 6, people living with dementia 6

S7) 25/04/19 DEEP Group Shrewsbury - people living with dementia 5

S8) 30/04/19 Alzheimer's Dementia Café Oswestry - carers 4, people living with dementia 3

S9) 08/05/19 Alzheimer's Dementia Focus Group, Bridgnorth - people living with dementia 4

S10) 14/05/19 Memory Service & Age UK group Bridgnorth - carers 8, people living with dementia 5

Telford & Wrekin

T1) 09/04/2019 Age UK Ketley Bank –carers 2, people living with dementia 4

T2) 10/04/2019 Age UK Morton Court –carers 2, people living with dementia 2

T3) 11/04/2019 Carers Centres Hadley, 12/04/2019 Carers Centre Leegomery, 25/04/2019 Carers Centre Newport - combined numbers carers 2, people living with dementia 1

T4) 24/04/2019 Age UK Apley Court - people living with dementia 1

T5) 10/05/2019 Alzheimer's Society Wellington - people living with dementia 4

T6) 13/05/2019 Rose Manor x2 family meetings - carers 3, people living with dementia 1

These enabled us to speak and gain comments from:

Shropshire: 35 people living with Dementia and 40 Carers

Telford & Wrekin: 13 people living with Dementia and 9 Carers

Each group gave verbal permission for the information to be shared with Healthwatch England and locally with the STP. In addition each group visited by Healthwatch Telford and Wrekin signed a consent form for their information to be shared with Healthwatch England and locally with the STP

For Shropshire, Telford and Wrekin all but one group member was White British. Only the DEEP group in Shropshire and the Alzheimer's Group in Telford and Wrekin had men who had experienced younger onset dementia.

Additional Material considered:

- Dementia Action Alliance Autumn 2018 survey 'Dementia in Shropshire and Telford & Wrekin'
- Healthwatch Shropshire Enter & View Reports to Care Homes registered by the CQC as providing Dementia care - recommendations as published on Healthwatch Shropshire website

Themes with the responses and key examples from multiple groups.

Comments are assigned the group numbers as shown above to indicate the source. (No differentiation is given to comments from carers or people living with dementia).

Diagnosis

- 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?

Common discussion points:

Receiving the diagnosis is often shocking and traumatic:

- "felt like crying but I had to keep saying to myself pull yourself together" S7
- "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" S1
- "When my husband was diagnosed with vascular dementia (several years ago) we were told at the time that they were only able to follow up with Alzheimer's diagnosis and so that was it for us" S2
- 'B & D would not remember being given the diagnosis' S8
- "The process was unbelievably horrendous; I was just told I had it and that was that" S9
- "It was a kick up the backside. I was in the medical corps in the army, I thought this was the end of my life but I realised I can live with it and go on" S9
- "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
- "Overall, the diagnosis was traumatic for family members and the patient themselves" T1
- "The whole process of diagnosis was very difficult for everyone, he felt very concerned for his wife and how she would cope" T6
- "Diagnosis was difficult, lots of mixed emotions. I was very conscious of the next steps however; this has proven to be as difficult when first diagnosed" T3
- Four males attended the Alzheimer's society focus group all have been diagnosed with dementia. Their experience of the diagnosis was emotionally hard and overwhelming T5

There is often a long time between the first visit to a GP to explain that a problem has been noticed to receiving the diagnosis:

- “It would be good if GP’s were less dismissive when the family highlights that a problem is developing”
- One couple it took over a year for the diagnosis to be given S3
- For 4 of the 5 diagnosis took over 2 years with a second scan being done S7.

Main Carers are often the first person to notice a problem has developed:

- “[I] first noticed a loss of sense of direction, it took 4 to 5 months to persuade him to go to the Doctors and a further 2 years before a diagnosis was confirmed.”
- “At the time we had a friends whose husband had dementia and he use to sit with him so he knew what was going to come.” S5
- Wives were reported as being the first people to really notice the differences 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. S7
- The family members commented on the most difficult part of diagnosis was the feeling they were not listened too, very frustrating process to go through. T2

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 1 or 2 scans. Most were in agreement that the process for diagnosis was as follows:

- GP refers patient to Memory Clinic who do questionnaires/memory tests. Some report that these tests take place at the Clinic, others had staff come to their homes.
- The results of these tests are sent to the Consultant who makes a formal diagnosis. At this stage some report being sent for CT scans, but not all.
- Following diagnosis the Memory Clinic then hold discussions with patient regarding meds
- “He went to the GP who sent him to the memory clinic where a scan showed Vascular & Alzheimer’s Dementia. He was not given any medication” S5
- It was commented that the tests done by the Memory Clinic during diagnosis don’t feel like they reflect the seriousness of the diagnosis S2

There was some reporting of misdiagnosis amongst the younger onset group

- Several were initially told it was nothing and don’t worry about it, with one GP saying he had similar problems. S9
- D reported going to the GP for a whole year each time answering the same set of questions. S9
- G was initially given antidepressants by his GP which he was not able to tolerate as they made him very sleepy. S9

- B found his GP to be dismissive and he had to demand to be seen for testing and a scan. S9
- Four of the group members were initially told by the memory clinic they had depression & stress, one was told he had obsessive compulsive disorder. S9
- “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

The level of information received at the time of the diagnosis was often too much or too little:

- “J reported that B had an assessment with the memory clinic and felt that 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
- “Alzheimer’s and Age UK both were very helpful with practical things like attendance allowance and council tax” S5
- Each contacted the Alzheimer’s Society and received a full box of information some of which was not appropriate for that particular time, although useful for later it was put away and not read. S7
- “You could be given information on what to search and where to find it, so you can go at your own pace”.S7
- All agreed that what was needed was some local information to begin with, “so that you don’t feel alone and can get help if you need it”.
- That information can be staged rather than all at once when you are not ready for it. S7
- “I think hospitals and GP practices ought to have pamphlets regarding support groups” S9
- “Lack of support from finding services. They were given lots of leaflets to various support groups and no guidance on where is best” T1
- “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.

Care Plans

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

On asking this set of questions most people had no or little knowledge of Care Plans:

- many not aware of the GP or memory service having a care plan S3
- Only a small number of the group were aware of a care plan being in place, or had seen a care plan.S1

- 4 out of the 5 had never seen theirs. S7
- “What care plans?” S7
- “Never seen it” S7
- “I feel I haven’t seen my care plan” S9
- “My husband doesn’t even know about this” S9
- “No idea what a care plan is” T5
- “if you need us, phone us. That was my care plan” T5
- Not a lot of knowledge for care plans, many commented maybe this was something that had been set up at first diagnosis. If that is the case it has not been reviewed or mentioned since. T1 + T2.

For those that were aware they had not found the Care Plan content or usage adequate:

- “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” G understood that the CCG had been highly rated for having care plans in place but he is concerned that it appears like this because of mistaken reporting caused by incorrectly recording data. S7
- “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” S9

Post-diagnosis

- 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?

The need for information continues:

- “We were not advised about changing the will so that there is tendency in common. By the time we did get the advice to do this it was said that he did not have the mental capacity. This was because they asked him questions he had no interest in like how much is the house worth. He was Air Force and would never have had any idea about house prices! It cost £800 to get register for power of attorney” S5
- “Post-diagnosis, we received a book of information that talked about the next steps and what dementia meant” S1
- “My GP practice are hoping to create and give us a leaflet that explains what dementia means to the person” S1
- “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.” S9
- Support was handed for support groups vis leaflets, there was no real guide to which path should be taken or which group would be more suitable. T1
- Family members commented that they had to find it out for themselves. T3

- One lady mentioned she had found a coping course about Dementia online (Free) it had helped her greatly however this has been cut due to funding. She says “That could help so many people2 T4

The need for support continues:

- “The post-diagnosis time is the most frightening. You really should have immediate support at this time to help with the shock” S1

Difficulties with hospital stays:

- During a stay at Birmingham Hospital for a heart operation B found that his ‘this is me’ was put in a draw and not referred to. There was a butterfly at the back of his bed head 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’. Also he was asked ‘have you had anything to eat or drink this morning?’ whilst on his way to theatre, fortunately his wife was present and had to explain about his dementia and reply on his behalf, which was embarrassing and distressing. “Why can’t they write it down on paper around your wrist or on you?” P had also had a hospital stay during which he took meticulous notes in order to manage his own medication as he did not feel the staff did it at the correct timings. When G had a hospital stay, he experienced difficulties with his medication being administered incorrectly for the majority of his stay. S7

Positive hospital stay experience:

- “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”. S8

Use of the butterfly symbol in hospitals:

- This worked very well whilst in hospital for a knee replacement operation in Robert Jones and Agnes Hunt Hospital, Gobowen. However this did not link through to booking appointments and the outpatient appointment itself. Appointment dept. phoned up and spoke with the person affected with Dementia to cancel an existing appointment and make a new one. He could only remember the person’s name nothing about the source or contact of the conversation. Therefore his wife had to search to find out who had called and why. Fortunately she was able to work this out otherwise they would have missed the appointment. “Could the butterfly symbol be embedded in call contact information?” S4

- At the outpatient appointment at RJAH (Gobowen), he was given a form to complete which he had to ask his wife to help him complete about his history. His wife had to explain that he had Dementia, several people spoke to him prior to going in to see the Consultant and each time his wife had to explain which was embarrassing for them both. Once in with the Consultant again he didn’t know about the Dementia. Whilst they were pleased at the operation and support for the knee replacement they were distressed by the lack of awareness of his Dementia. Which they found embarrassing. S4

- “They put a butterfly above the bed [in the hospital] but that was it” T5

Preventing hospital stays:

- One carer recently experienced Integrated Community Care ICS. This worked extremely well after her husband had fell and had a urinary tract infection. A social worker visited and put in a package of care for 2 weeks which included getting walking equipment 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. S3.

- "I phoned the memory service and within 2 hours the problem was sorted" S10.

Groups are valued especially long standing ones:

- A Lady 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. They are considering the new share & care run by Shropshire RCC as the sort of environment they would like. S3
- "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." S6
- "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." S8
- 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. S10
- "I like coming to here (dementia football he is driven by group leader) it's very friendly" S2
- They have in the past gone to 'Singing for the Brain' in Shrewsbury, 'Odd Fellows' friendship group in Oswestry' S8
- Some group members had tried a variety of groups or researched into groups. Many groups on offer are activity or discussion based which were often not age appropriate to the younger members of the group e.g. the song choice at singing for the brain was from a different era. The DEEP group is very supportive and each member feels a sense of belonging which has affected other aspects of life. P explained how knowing the others had helped motivated him to take more care over his appearance and dress as he didn't want to let the others down. 'I find apathy can be a problem, finding like-minded others makes a huge difference'. DEEP groups were established when G applied for a grant from the CCG. S7
- "The 'Singing for the Brain' groups is what keeps us going."S1
- "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" S1
- "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" T2
- "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!" T5
- "You go to other things, as soon as you say 'dementia' they look at you like you're totally thick" T5
- "I love gardening, but no gardening groups available. Me and my wife would love to still be able to enjoy these things together" T5.

The Memory Service received mixed reviews about how helpful the intervention and support had been:

Positive

- “The memory service is our sanity.” S10
- “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.” S1
- “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. S3
- The Psychiatrist had visited one couple who found that extremely helpful. They were able to go through the medication in detail. She will be returning within 3 to 4 months. S6

Negative

- It was the experience of one person 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. S2
- “The memory nurse came this Tuesday, she is finishing soon but we never felt supported by her. R thinks the people on the TV are real so he offers them food at meal times and talks with them. She just said turn the TV off then. It all felt like a tick box exercise. And for us we never felt supported, they come every 6 months but there is never any feedback” S5
- One person had such a bad first experience when being told of the diagnosis that he has refused to have anyone from the memory clinic back into the house. S6
- “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
- “The MPFT Memory Service is closing 2 support groups and 2 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 2 are merging what is the reason? Given that there are over 4800 people in Shropshire with dementia there is only sporadic support available. Al’s Café is one of the groups closing. It was originally a Cognitive Stimulation Therapy Group.” S7
- Memory service was mentioned by two family members, they both described the service as “not a great service, lost touch with them” T3
- “No follow up to see how we are, which groups have helped us etc.” T5

There was considerable confusion around being able to continue to drive a car or not, how you are assessed, informing the DVLA and when to stop driving:

- “the bombshell was when she said I couldn’t drive. I have driven all my life it was my job. I’ve driven lorries and coaches up and down the country. I don’t think our marriage would have survived if I couldn’t drive I will not let her get away with anything.’ ‘I never want to see the person who hold me that again. She use to like to come to our house but she sat at the table and told me I couldn’t drive. But my wife sorted it out’ ‘I’m driving now but it is a good job as my wife has cancer and I'm her carer. We had to keep going over to Shrewsbury for her chemo." S2

- V gave up driving when she found it difficult to turn at her T junction because of having to turn head quickly. She was never told that she could not drive. S9
- "During a check-up for his heart we mentioned to the nurse that he was struggling to get the car into gear when driving up the lane to the house (it is very steep). She told the GP and he unfortunately stopped him driving but said we could appeal. By the time we phoned Shrewsbury for an assessment the DVLA had stopped his licence so he had to go to Birmingham instead where you are tested off the roads. The Psychologist, Occupational Therapist & Driving Instructor took all day with him. He talked all the way through the test. It was a blow when they decided he couldn't drive. This could have been handled better. He still feels that he should get his licence back." S5
- "Having my driving license taken away was the worst. The most frustrating thing was I had used my own car for year to get around and now I would be left to figure out buses, taxis and no support for this" S5

Using public transport:

- "A service for providing us instructions on which buses or trains to take places would help me see my friends" S9
- "When going on holiday we always sort extra help from trains or airlines so that a good quality of life could be maintained for as long as possible." S3
- "I did manage to get us to London 2 weeks ago. The train down is fine because you can ask the train company for help but the underground I was dreading. Actually it was better than I thought he held onto the big bag handles I was carrying and I kept pulling him in the right direction" S5
- "For the past 6 years they have spent 3 to 5 months each year over the winter period with close friends in New Zealand. This year D did find the journey taxing. The airline where extremely helpful and took very good care of D." S8
- "More support for those who need public transport, easier routes and more direct stops" T6

Incontinence no longer any advice and help:

- Prompt help when asked for (is needed), one lady asked for help because of her husband's incontinence but the help took a long time to arrive. S3
- "Did once have an incontinence nurse a long time ago. No help available for this now, just buy pads but they are not very affective. Night time is the worse for this and the bedding is often soaked" S5

A great deal of discussion centred on GP surgeries including appointments and the level of support from the GP themselves:

Positive

- They both were at the Plas Ffynnon Medical Centre. He felt throughout the time he cared for his wife he felt very well supported by the GP. S8
- "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) S1

- “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

Negative

- There was concern about the inconsistency at GP practices; in getting appointments, things being cancelled or in consistency of who you can speak too. Some GPs seem to 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. S1
- “You have to fight to get the GPs out to you.” (Riverside Med Practice) S1
- “Getting a GP appointment is very hard.” (Bridgnorth Medical practice) S10
- “Closer communication between the GP and the memory service regards medication would be helpful” S3
- “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. P sent a paper copy of this to every GP practice in Shropshire” S7
- “The GP never asks me how I am coping.” S1
- “For me support from this group but not much from the GP.” S1
- “They [GPs] don’t believe people that young have got it” S5

Support for families/ carers

- 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?

Massive need for ongoing practical help and support expressed in every group:

- “Care into the home – especially like those care providers who can come and 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.” S3
- “Carers and patients need practical support, not policy.” S1
- “We are learning mostly from groups and through others experiences.” S1
- Family paying for a carer to come into the home - really good at chatting as well as helpful. Nice to be asked how everything is going. This is very helpful as there are no long term relationships with Church Stretton and the family is mostly overseas. S6
- Carers need support. “We lose what we thought we’d have in our retirement and they lose the person they had”. The group acknowledged that their wives can feel angry and alone. Admiral Nurses support the family unit and the person themselves and can be useful in times of crisis. G’s wife sees them once per month. They all expressed worry about what their wives will have to manage. S7
- “I feel like people who live in other areas are getting different levels of support [sometimes better]” S1
- It was agreed that most support came from carers groups, or talking to other carers and sharing experiences. S2

- “It would be nice to have someone come and tell you that you are doing the right things” S5
- “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?” S1
- “Admiral nurse has been wonderful.” S3

Respite care is needed:

- “Respite care very important – particularly liked a local care home where someone could be dropped off in the morning and then collected after lunch.” S3
- “The only respite we’ve been offered if some a few days to a week, as a one off. But what we need is ongoing support for a few hours a week” S2
- G’s wife went to a Swan Mere Day Centre in Ellesmere 2 to 3 days a week between 10 am and 4 pm, therefore he had the chance to go home and sleep, which was and continues to be excellent resource. He did try at the suggestion of his family to have carers overnight as his wife would often be calling him 4 or 5 times in the night. However partly because of the cost and partly because he still woke he cancelled this after 4 months. S8

Communication breakdowns between professionals:

- Communication breakdowns between professionals leaving family members frustrated having to repeat themselves over and over when reaching out for help. T2

What matters most to you?

- When people are designing services what do you think is most important in order to improve the experiences of people with dementia and their carers?

Very individual comments

- “Driving assessments” S9
- “Help with directions and transport for people who need to go places” S9
- “We don’t know how to get places” S9
- “I miss my friends, I can’t get on a train and just go see them anymore” S9
- “Support with activities of interest like gardening, fishing and bird keeping/showing.” S7
- “Loss confidence and motivation happens so things which can prevent this taking over.” S7
- “Someone to help with motivation so that it doesn’t fall back upon the wife all the time.” S7
- “It’s old feelings of not wanting to be a burden.” S7
- “I miss male company having been use to a male dominated work environment.” S7
- “Man shed would not let me join as they were worried about the danger of power tools, they thought I might cut my hand off or something!” S7
- “Not necessarily specialist things but dementia friendly groups would be good.” S7
- “Feeling that the CCG & Council are supportive and listen.” S7
- “Help with transport and travel.” S7

- A fear of nursing homes was discussed because of current experience with relatives who have dementia and are living there. One nursing home was mentioned as having poor care and hygiene standards. S7
- “Dementia patients need to do more activities such as men’s and women’s club.” T2
- “Making transport easier for evening/night visits.” T4
- “Stop taking away what we’ve got, there’s not much as it is.” T5

On-going practical help and support for carers

- Most of the group agreed that consistent support to give them some 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. S1
- “If once a week for 2 hours, on a routine basis (every Wednesday for e.g.) a carer could come and be with loved one, so that we had some protected time. Not to go to meetings or appointments, but for us.” S1
- “Time where you know your loved one is safe and you don’t have to be on call” S1
- “Planning who to ask for help can feel like a marathon sometimes” S1
- The group felt the most important thing is GP support. Most felt they were very lucky to live in Church Stretton with the Mayfair Centre and lots of community groups. S6
- “Someone to come talk to my husband or his life etc. Or someone to take him out for a coffee. Someone who can come to your house for an hour or two and look after your loved one whilst you pop to the shop, this is invaluable.” S2
- “Someone you can ring in a crisis for help and advice (not just through the week, but out of hours and weekends)” S2
- “More support with signposting, where should we go and why?” T5
- “Supporting our admiral nurses.” T1
- “That as a family we feel their safety and our emotional support is a priority.” T6
- “Raising awareness, better preparation. This is life changing for the patient, their families and their carers.” T1
- “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” T2

Appendix 4: Adults with Learning Disabilities and Autism. Focus group report

The focus groups with adults with learning disabilities were organised and led by Taking Part, an Independent Service for people with Learning Disabilities.

Report

NHS feedback draft
Shropshire and T&W

Quotes from group work to illustrate general statements

Main themes

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)’.

Just how much carers are important, 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.. But also for emotional support and help with understanding processes and choice making.

- ‘Even now I am constantly misunderstood by people’ (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.’

Specialist health-care services

There was good feedback from both sides of the county with regards to specialist care, but it’s important to highlight here people’s understanding.

Most people we talk to 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.

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'

Expert by Experience group

The key elements that self-advocates feel would help to stop the health inequalities that they know people with learning disabilities and autism experience throughout the health service

Consistency.
Access to the same doctor is vital (know me well) i.e. know me when I feel well, know what's normal for me. Parity across the county with AHCs.

- '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.'

Communication.
Don't assume I understand because I say I do, reflect /check. Better training for Health-workers

- '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)'.
- 'Easyread 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'
- 'Do workshops, like the Wise up Shape ups (Taking Part and RCC co-organised) for Day Services in Shrop. & T&W 'they were great.'

Compassion.
Understanding I am a person not a 'condition' and 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..)

Appendix 5: Feedback from public events - 'What would you do?'

Event participant demographics

	Shropshire	Telford & Wrekin		Shropshire	Telford & Wrekin
1. Your age			**3. Do you consider yourself to have a disability?**		
Under 18	0	0	Yes	4	3
18-24	0	2	No	7	3
25-34	0	1	I'd prefer not to say	0	3
35-44	1	0	**4. Are you a carer?**		
45-54	0	1	Yes	2	4
55 -64	4	1	No	9	5
65-74	3	3	**5. Do you have:**		
75+	3	1	a long term condition	2	2
2. Your ethnicity			multiple conditions	3	0
African	0	0	Neither	6	7
Arab	0	0	**6. Which of the following best describes you?**		
Asian British	0	0	Heterosexual	8	9
Bangladeshi	0	0	Gay or lesbian	0	0
Black British	0	0	Bisexual	1	0
Caribbean	0	0	Asexual	0	0
Gypsy or Irish Traveller	0	0	Pansexual	0	0
Indian	0	0	Other	1	0
White British	10	9	**7. Your gender**		
Pakistani	0	0	Male	7	5
Any other white background	0	0	Female	3	4
Any other mixed background	0	0	Other	0	0

Other	1	0	Prefer not to say	0	0

How can you be supported to live a healthier life?

What is stopping you from living a healthier life?

Shropshire

- Social Isolation- not knowing where things are.
- Rural Isolation
- Cross Border- Communications between services (Shrops- Powys, Shrops- Telf)
- Cross Border- Services answer to different Authorities with different priorities; who do they listen to?
- Mixed messages
- Time
- Lifestyle
- Self (motivation)
- Contact with services
- Access to services
- The ability for us (locally) to have enough services for people to be seen
- Transport (e.g. discharge from hospital; live in Market Drayton, taken to PRH by Ambulance, upon discharge have to get a taxi as bus between Market D- Telford)
- Communication from services- particularly Social services
- Continuity of care
- Rehab Officer at Shropshire Council (for Visually Impaired) has huge waiting lists
- Not enough staff to cover the need
- Access (in cost as well as location)- accessibility of services, access to staff, access to opportunity
- Early intervention- consistency and regularity of intervention
- No relationship with services (e.g. no named GP)
- Poverty/Lack of money or ability to access services

Telford & Wrekin

- Loneliness
- Various degrees of isolation can affect
- Worker with homeless people finds it difficult to access services and getting providers to work together.
- Lots of pressures.
- Time limited appointments/being rushed.
- GPs not spending time with people.
- Carers need help themselves but don’t get it.
- Money – people not able to work due to illness (e.g. Mental Health) or not financially aware.
- Live alone and have home deliveries – usually buy small amounts of food but charged for the delivery because order is under £40.
- Transport for GP/hospital appointments cannot afford costs & lack support.
- Food – lack of money/information.

- Early intervention – don't know where to get it from.
- Time to do everything.
- Lack of education in schools from an early age
- NHS 111 direct people to hospital instead of other areas.
- Homeless people – they still need caring for and have a right – people are turned away as they have no fixed abode.
- Lack of advertisement on available appointments.
- Waiting lists to access primary care services.
- Focus on academic achievements in schools etc – instead teaching Kindness etc
- Local funding cuts to 3rd sector/voluntary sector organisations who are meant to help or people being signposted to.
- Too much choice – supermarkets.

What could help you to live a healthier life?

Shropshire

- Organisations should be leading on what messages the public listen to, be the trusted voice
- Make services friendly and comfortable
- Need to treat **me**, the person
- Moving away from the medical model to social model
- Specific information about issues/conditions given, not just treatment but community support
- Primary Care Networks- sharing knowledge and experience amongst organisations
- Community hubs (*care would need to be taken when defining what is a 'community', not just north/south)
- Mindfulness
- Shared services/facilities between organisations (e.g. Community nurses on mobile libraries)
- How the public receive information- should be simple
- Organisations to send information/best practice etc. to existing trusted networks (e.g. Parish Councils)
- Service awareness (awareness of other options within the services themselves)
- Easier access
- Health promotion (this should be done at an early age, services linking with education services)
- Information about how to access help; where do you find out whats out there
- Communication (about services with the public)
- Communication (with other services)
- Communications (how information is presented as well as accessed)
- Adopt a model similar to the Disability Oswestry one (list of services for needs)
- Research into future prevention
- Addressing access issues for people facing deprivation (all forms; rural, urban monetary)
- 'The channels of communication need to be appropriate for the person'
- Strong Communities- cascade information throughout generations, older people helping younger people vice versa

Telford & Wrekin

- GP and other organisations talk to each other and have a register for people who live on their own.
- Early intervention.
- Recognition of… (leading unhealthy lifestyles/healthy lifestyle or conditions)
- Raising awareness – mental health.
- Promoting what's going on locally – getting together, walking groups etc…
- That's its ok to seek help and not a failing.
- Care navigators – knowledge to know what is important to you.
- Consistent support in schools.
- Things being picked up earlier in school like Autism…
- Get it right earlier.
- Reduce isolation.
- Organisation to link up.
- For organisations to be aware when people live on their own like GPs etc. IT from different organisations need to talk to each other. Telephone call to check up on people who live alone, say once a week. British Red Cross do.
- Free home food deliveries for people who live alone.
- Reliable suppliers for home deliveries of food who check quality.
- Better donation to food banks

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

Shropshire

- Motivate people
- Professionals to take time for people- find out what they need, and how to achieve this
- Investment in professionals- more of them, better communication skills etc.
- Investment in services & local people- taking time to educate and understand people will help to relieve service strain further down line
- Access to services when I need them
- Encourage public to use other Health professionals- educate people and raise awareness of alternative access points (e.g. pharmacy, nurses etc.)
- 'Ask my GP' service (business/system model)
- Better spread of services around the county
- Shared services and shared knowledge
- Treating 'you' as a person
- Standards of service
- Rural Access
- Communication- not just technology solutions (better communication between the health & social care services)
- Communication- different methods of access (not everyone wants to join a group)
  -not everyone wants to/can use technology
- Early access- in life (e.g. teaching skills and raising awareness at young ages)
- Currently targeting people when they are already sick- needs to happen before this
- Targeting communities as well as the individuals (for prevention)
- Revised services for the modern day- addressing modern issues, free at point of access etc.
- Timely availability (of services, rehab, support etc.)

Telford & Wrekin

- Care navigators for everyone.
- Emotional support
- Intergenerational stuff.
- Easy access to useful information.
- Emotional intelligence – not taught in schools and should be.
- Trained staff in a range of services who can signpost.
- Support people through adolescence and beyond.
- Community/organisations share resources and offices. Need to know what’s out there. Work together for sake of person.
- Replace services if lost - like British Red Cross service recently stopped.
- Organisations work in partner.
- Community eat well event – promote healthy eating, provides social contact for people and help reduce loneliness and isolation.
- Better advertisement.
- NHS working with other partners to provide information, services, share best practice and for organisations to stop being protective of their own areas.
- More recognition on third sector services by organisations.
- Awareness/education in school around physical/emotional health – involve families in education.
- To have “Kindness” running through everything they do.

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

- Better education – early stages! Schools (physical and mental health).
- Transportation made easier (potential home visits/digital communication.
- More effective communication i.e. referrals between services, battling between services "who takes on this patient".
- Connecting services! Signposting external services like Police.
- Recognising the importance and value of each individual(emotional/social) care plan and person centred.
- Recognising the importance of third sector (going back to funding. GPs etc. recognising what each organisation does and how fantastic the service they. provide are – the benefits from the third sector – professional need to know.
- Improving NHS 111 service – trained professionals.
- Social and emotional and psychological support for carers.

What is your experience of care and support now?
Shropshire
• Traditional GP services being moved to hospitals i.e. ear wax removal, phlebotomy • People having to pay for alternatives ear syringing services • Transport cuts impact people's ability to travel to hospital • Chiropody services cut from GP surgeries leads to impact on those with diabetes or sight loss e.g. not having the correct foot wear for walking around on the wards. • Prescribing for UTI over the phone • Hospitals paid per procedure, GPs paid one lump sum to cover all services • Hospitals not communicating well enough on what services are available in the community • Difficulties contacting GP and Hospitals • A&E long waiting time for X ray & treatment • Arthritis - lead to a swollen finger and a ring needed to be cut off. Jewellery shops would not do it. Went to A&E. Long wait for simple cutting off of ring. Needed different place to go for simple help • Cancellation of eye appointment lead to emergency admission in a Birmingham Hospital • When having cataract removal from one eye and needing the other eye done why are you discharged and have to start the process again? • Rapid Support team worked very well. Elderly person admitted to respite home for 1 week then because the council would not fund a place at that care home she had to be moved to another one half an hour journey from her family. • Rang by acute trust with a next day appointment due to a cancellation. On arrival at the clinic told that it had been cancelled as the Doctor had had to go to A&E. The on getting home phoned appointments who phoned her back in 40 mins with a new appointment and thanked her for letting him know as otherwise he wouldn't have known the clinic was cancelled. • Two acute hospitals have very different cultures • Appointments – end up with 2/3 sheets & telephone calls per appointment, and repeated if appointment cancelled- wasteful. • Cross border communication within the eye service poor. Children's school picked up an eye sight problem which were already being dealt with in one county. They referred to neighbouring county services – confusion and repeating of messages followed.

- Haematology –outstanding care.
- Lack of equality within service provision -Seems that care is either excellent or terrible with very little in between. Striving for excellence is all well and good but what about a good level across the board.
- E.g. of excellence –following an operation saw GP, referred to RSH same day appointment with Orthopaedic clinic. On the other hand also experienced terrible care when he nearly had a procedure done by someone who was not qualified to perform it.
- Emergency colectomy brilliant care however once on a general ward nursing staff were in tears as they were so stretched, when leaving the hospital left without the correct information about her diet. Should have been more links between hospital and community care. Lady had no point of contact, when ringing back the hospital spoke to a different person – no continuity of care.
- Had kidney out felt very unsafe
- Survey of people affected by Dementia overall reported negative experience. Shouldn’t be as negative as is.
- Patient/ professional relationship – some people good with different caseloads.
- Expectations of the public from staff is ‘big’. Younger generation shifted to ‘me’ and ‘immediately’.

Telford & Wrekin

- Battle between GPs and mental health services (depending on level and intensity)
- Support for whole primary regarding Dementia (Admiral nurse) lack of carer support.
- As a parent – more emotional support provided for children with disabilities.
- Lack of emotional support (Long Term Conditions).
- Limited access to GPs appointments.
- A lot more services available.
- Misunderstanding between location.
- Acute system – good experience.
- Lack of follow up support (Community support).

What small changes would make a difference?

Shropshire

- GP digital screen used as notice board- falls clinic information, local groups linking with the social prescribing
- Complex care- one person to contact who takes responsibility rather than multiple contacts and this person needs to have good local knowledge, to be able to also disseminate information to other professionals/ carers involved on key information like medication.
- Anxiety of waiting for urgent appointment. Why not text, email or use the quickest form of communication rather than waiting for letters.
- Don’t outsource appointment letter sending.
- A shared care plan that works.
- Sharing of information- to correctly work through what is confidential material and correctly share. E.g. Two consultants not sharing with each other the results of a test and neither sending information to GP. Not all GPs on EMIS. Why so worried about data & confidentiality when need to have information shared in secure formats.
- Joined up cross county working
- Continuity of forms – for patients and professionals

- Staff supported to know each other across services in-order to assist with communication and joined working.
- Staff feeling over stretched – help with this
- Adult social care – Shropshire is the lowest paying into nursing home care but the highest into domestic care support
- Timely assessments
- Clear communications including visually clear (different colour papers)
- Reduce emergency inappropriate calls – improving public information
- When a larger person falls – need help to get up and correct equipment could be first responders with the correct equipment rather than ambulance. Person may not always need to go to hospital.
- ‘2 in a car’ Operating in Ludlow & Bridgnorth - go around at night could potential extend their service to include getting people up off the floor if they have correct equipment and monitoring e.g. Blood Pressure, documenting information and linking with the GP.
- Help with mattress turning
- Better joined up services between hospitals and community
- Re instate certain services to GP surgeries like Phlebotomy, ear wax removal and chiropody
- Increase in number of geriatric specialists
- Driving safety – information sharing with the DVLA re certain conditions
- Digital records – professionals can access patient information quickly
- Culture change with regard to falls prevention on general wards, patients not getting out of bed to walk

Telford & Wrekin

- Having a local point of advocacy (access) for signposting for extra support, continuing support and prevention.
- Better education - early stage (school).
- Increase in council tax (education)
- Improve communication.
- CCG to fund & support local issues to voluntary sector e.g. healthy living.
- Locums - course to advise them what is available at the moment. Easy access/information.
- Transportation - easier access/transport system. Home visit.
- NHS 111, review service – doesn’t gain anybody’s confidence and there is a lack of training.
- GP surgeries – better telephone system.
- Statutory third sector working together (referrals)
- Care in the community (Nurses)

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

Shropshire

- Continuity of communication for individuals across the services, also clinical so-ordinated communication & honest & clear communication
- Specialist visits to GP services to work alongside GPs with complex needs to skill share

- Physiotherapy attached to wards to enable patients to walk
- Increasing rehab staff and OT provision
- Multi-disciplinary working – knowledge and skill sharing
- Better housing which works for people they age
- Retirement villages where care levels can increase when needed.
- IT which joins up ambulance, GP, Hospital services, covering situations likes falls.
- Social services and NHS to work together – need to be one organisation
- Shared budgets
- National Health Service rather than fragmented e.g. preventing difficulties when living on the borders currently mixed - living in Wales don't pay for prescriptions but can't choose which hospital to go to.
- CCGs should not be able to go against nationally set guidelines e.g. Shropshire has no admiral nurses in Shropshire. Also national pathways which include specialist help & dementia navigators not available in Shropshire
- Why not regional/ across an area planning

Telford & Wrekin

- Commissioned not grant funded.
- Regulating how money is invested.

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

- Education – children and young people.
- Support groups.
- Knowledge of services/where to go.
- Signposting – issue- GP's.
- Family/friends support (emotional).
- Regular exercise – anything simple/intense.
- Food and drink guidelines information.
- C.L.A.N.G
- Groups – for socialising/out in nature/fresh air.
- Positive Mental Attitude (P.M.A) – Behaviour, attitude and mediating.
- Information in community.
- Online guides, information and support.

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

Shropshire

- Mental and physical activities
- Research
- Reading
- Walking
- Be involved in the community/ with organisations
- Internet search: symptom checkers
- Socialising; family, friends, people of different ages
- Motivation/ Resilience
- Quick and easy access to someone- support and advice
- Self-motivation
- Groups e.g. walking groups in the community
- Physical exercise and mental exercise
- Read and search for information
- Volunteer, socialise, groups, community involvement
- Charity groups/support

Telford & Wrekin

- Signposting/barriers – find the right person.
- Digital services; location, affording, skills, fear and understanding.
- 24-hour access/extended.
- Specialist clinic; further expert support.
- Transport – bus routes, too far away, medical transport – need more. Fear and anxiety travel training.
- Disability access – Environment/transport – mobility.
- Holistic – GPs and staff approach.
- Surgery approach/building/environment.
- P.M.A – first point of call/being kind/practising mindfulness = builds confidence for patients.

- Better communication between services – No duplication – identify gaps.
- Individualised appointments: looking at the entire person – more time with GP.

What would help you take control?

Shropshire

- Assistance- impairment
- Be offered information/guidance- recognising to be mindful and self-aware
- Awareness of google searches e.g. NHS Choices
- Awareness of care and share groups (dementia)
- Peer support groups
- Too much information- contradicting, always changing
- Flexible approach to working e.g. shifts
- Information given in an appropriate way- signposting/social by professionals
- Early educations
- Attitude change
- Remind (especially) children/ young people to connect with people physically, rather than by mobile
- Helpful guidelines (food/diet)- to not keep changing
- Joining and educating young people and generations to volunteer, join groups and be part of society
- Attitude change
- Cultural shift/change

Telford & Wrekin

- Nothing recorded

If you need help to take control of your health and wellbeing, who would you like to help you? How would you liked to be helped? When?

Shropshire

- Recognising carers involvement. Value people
- Taking action early with help/case- HCA’s
- Mental capacity conversations- tailor the approach
- Reduce stigma/labelling- shouldn’t be the only way you can get care
- PPG’s- what if not everyone can use technology?
- Bring in new models, but don’t rule out what is already in place
- Person centred approach
- Resources in the community
- Inclusive approach
- Something under ‘one roof’- point of contact
- Prefer to have help from elsewhere, rather than a GP
- Peer support groups
- One point of access with; knowledge, support, who do I see?
- Take action earlier- using groups

- Education
Telford & Wrekin
- More local services closer to home. - More social care input – at home and understand needs. Preventative needs. - Availability and access for people at work i.e. shifts. - Free health checks at work? - Community sharing resources and knowledge of groups - Employers – understanding/flexibility. - Fast/rapid/right treatment – straight after. - Mental health support. Mentoring and coaching - Information, advice and guidance service – single point for everyone. Skilled/trained/24:7 for specific areas. - More community fridges.

Event participant feedback

	Shropshire	Telford & Wrekin		Shropshire	Telford & Wrekin
1. The topics were well explained			5. There were enough opportunities to participate		
Strongly Agree	3	8	Strongly Agree	8	10
Agree	5	5	Agree	3	3
Good	4	0	Good	0	0
Disagree	1	0	Disagree	0	0
Strongly Disagree	0	0	Strongly Disagree	1	0
2. The speakers were well prepared			6. The event helped me to understand local issues		
Strongly Agree	4	9	Strongly Agree	2	8
Agree	3	4	Agree	5	5
Good	3	0	Good	2	0
Disagree	2	0	Disagree	3	0

Strongly Disagree	0	0	Strongly Disagree	0	0
3. The presentations were interesting			7. The event was well organised		
Strongly Agree	2	8	Strongly Agree	6	9
Agree	7	5	Agree	3	4
Good	2	0	Good	2	0
Disagree	1	0	Disagree	1	0
Strongly Disagree	0	0	Strongly Disagree	0	0
4. The table discussions were good			8. The room and facilities were adequate and comfortable		
Strongly Agree	4	11	Strongly Agree	6	9
Agree	6	2	Agree	3	2
Good	1	0	Good	2	1
Disagree	0	0	Disagree	1	0
Strongly Disagree	1	0	Strongly Disagree	0	0

Additional comments:

Telford & Wrekin

- Sometimes a little “jargon” in CCG presentation
- Good to see Shropshire and Telford and Wrekin Healthwatch working so well together
- The talk was interesting – I await the action
- I got a lot from today and discovered some groups can be self-referred to or turn up as a drop in
- Healthwatch information stand was very good
- Information on the tables was excellent
- Introductions on the table I was on actually did not take place. I have no idea of the names / organisations that people represented. Maybe do name plates
- Introductions was good and checking that people could hear was important
- Topic covered and material presented was excellent / good slides
- Speakers were definitely well prepared

- Table discussions – everyone on my table actively took part and made contributions. It was a good relaxed atmosphere. I liked the fact that we had three different facilitators come to the table.
- The room was good, facilities and refreshments also.
- A successful event, well done.
- I can’t wait to see the final report.

Shropshire

- Very noisy outside the room
- Hearing was difficult. The sound didn’t flow well in the room- PA system would help
- Very noisy from other rooms. Made it difficult to hear
- Some of the presenters slides were too small to read at the rear of the room
- Noise from other groups outside the room prevented hearing whole of presentations.