

What matters to you? - Personalised Care Survey

Engagement Summary Report

August 2021

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Executive Summary

Between 1 July 2021 until 1 August 2021 a survey was conducted to engage with the populations of Herefordshire and Worcestershire, with the purpose of gauging an understanding of 'what matters' most to people when it comes to their own health and wellbeing, in the context of personalised care.

100 people responded to the survey.

Results

A summary of the results can be found below. It must be noted that none of the questions were mandatory, and percentages have been worked out based on number of people who answered each individual question. The respondents told us:

- 94% (94) answered the survey for themselves, about their own experience.
- 67% (37) talked about their experience of using their own GP/Doctor's surgery.
- The average score respondents gave when asked to rate how involved they felt during their experience, was a 6 (slightly involved).
- Respondents rated their needs and priorities being listened to as a 6 (slightly listened to), on average.
- The average score respondents gave when asked to rate their ability to ask questions during their experience, was a 6 (slightly listened to).
- Respondents rated their experience of being able to ask all the questions that they wanted to during their experience, as a 6 (slightly listened to), on average.
- On average, respondents rated how well they understood the options available to them about their care as a 7 (slightly understood).
- Respondents rated how involved they were in planning the next steps in their care, as a 6 (slightly involved), on average.
- On average, respondents rated how well the professionals or services supported them to manage their own health and wellbeing by themselves / at home as a 5 (slightly not supported).
- Respondents rated how confident they felt about where to go to ask questions or seek support after their experience, as a 6 (slightly confident), on average.
- On average, respondents rated how easy they found it to access useful support and information by themselves, as a 6 (slightly confident).

Comment Analysis

Question	Comments			
	Positive	Negative	Mixed / Neutral	Not clear
How involved the person felt during the session.	18	25	6	3
How much they felt their needs and priorities were listened to	19	23	3	7
How easy was it for them to ask all the questions they wanted to ask.	15	22	8	5

How well they understood the options available to them about their care.	14	23	5	2
How involved they were in making a plan about the next steps in their care.	18	19	6	0
How well the professionals or services support them to manage their own health and wellbeing by themselves / at home.	9	21	9	1
How confident they felt on where to go to ask questions or seek support after their appointment.	18	17	1	4
How easy they found it to access useful support and information by themselves.	11	18	4	5

The key themes are broken down in more detail in the body of the report.

Demographic breakdown

A demographic breakdown of the respondents is listed below. Please note - questions were not mandatory. Percentages have been worked out based on number of people who answered each individual question.

- 21 (21%) wanted to be involved in the development of the Personalised Care Strategy.
- 80% (37) of respondents were from Worcestershire.
- 43% (19) of respondents were aged 65-74.
- 35% (16) reported to have their day-to-day activities limited because of a health problem or disability.
- 38 respondents stated they had a disability, based on the definition given from the Equality Act 2010.
- 57% (27) of respondents were female.
- 95% (42) people who answered this question, reported to have not gone through any part of the gender reassignment process.
- 85% (39) of those who completed this question stated they were heterosexual.
- 74% (34) stated their ethnicity was "White - English / Welsh / Scottish / Northern Irish / British".
- 33% (15) reported to be carers.
- 96% (43) had not given birth or had become a parent to newborn baby within the past 26 weeks.

Aim

The health and care organisations across Herefordshire and Worcestershire are committed to providing people with choice and control over the way their health and care is planned and delivered. The project team were interested to hear 'what matters' to people when it comes to their own health and wellbeing.

The project team were particularly interested to hear:

- How involved individuals feel in decisions about their care and treatment within the service(s) that they access.
- How people's individual preferences and priorities are acknowledged by the service(s) that they access.
- What makes people feel engaged in their health and care.
- How people manage their own health and wellbeing independently.
- The resources and information people need to live well.

The feedback received will be used to inform the CCG's approach and development of the Personalised Care Strategy.

Background

Personalised care was identified as one of five major practical changes in the NHS Long Term Plan (LTP) and is relevant for the whole population, across all parts of the system. It is about people having choice and control over the way their care is planned and delivered, based on 'what matters to me', recognising the importance of an individual's strengths.

For this to happen we need to work together as communities, professional services and health and care systems. The NHS LTP explains six ways to make personalised care a reality:

1. **Shared decision making:** Working with health and care providers to make management decisions that best meet an individual's needs and priorities.
2. **Personalised care and support planning:** Care plans that focus on an individual's priorities and strengths. Empowering the individual to be actively involved in their care.
3. **Personal health budgets and integrated personal budgets:** An amount of money which can be used to choose support to best meet the health and wellbeing needs of a particular individual.
4. **Supported self-management:** Individuals are encouraged to make use of appropriate resources to maintain their own health and well-being. This might include peer support and health coaching.
5. **Social prescribing and community-based support:** Link workers spend time with individuals to understand their health and wellbeing needs. They then signpost them to relevant local support.
6. **Enabling choice:** Providing a choice in how individuals access services and in choice in how they receive support.

More information about Personalised Care can be found at:

<https://www.england.nhs.uk/personalisedcare/>

Exercise Summary

Active Period	1 July 2021 until 1 August 2021
Method	Survey (Survey Monkey)
Reach	Appendix 1 Those contacted were asked to circulate the survey wider to their own contact lists and networks
No. of Respondents	100
Results Key	<p>Qualitative Questions</p> <ul style="list-style-type: none"> Key themes have been established and listed. Example verbatim comments are listed within the text. <p>Quantitative Questions</p> <ul style="list-style-type: none"> The most prevalent answer has been highlighted in blue.
Interpretation of Results	The results have been reviewed and analysed. It is acknowledged that this method is subjective and open to interpretation. The full verbatim comments received have been shared with the project team anonymously and are available for relevant stakeholders to view on request.

Survey Results

Question 1 - Are you answering this survey for yourself or on behalf of someone that you support or care for?

Answers	Count	Percentage
For myself (the answers I give are about my own experiences)	94	94%
On behalf of someone else (the answers given are those of the person I support or care for)	3	3%
About someone else (the answers I give are about the person who I support or care for)	3	3%
On behalf of a staff group or organisation (please tell us who)	0	0
Other / Name of organisation or group	0	0
Answered question		100
Skipped question		0

There were 100 responses to Question 1, in which most respondents (94 / 94%), advised that they were completing the survey for themselves.

Section A – During the experience

Question 2 - Which health or care service would you like to tell us about?

Answers	Count	Percentage
GP / Doctor's Surgery	37	67%
Hospital outpatient	11	20%
Hospital urgent care	3	5%
Social care	0	0
Other (please specify)	4	7%
<i>Answered question</i>		55
<i>Skipped question</i>		45

Just over half of respondents answered Question 2 and continued with the rest of the survey questions. Of those who responded, 67% (37) advised that they would be talking about their experience of using the GP / Doctor's surgery for the purpose of the survey.

Other answers included:

- "All of the above"
- "Community Psych Nurse"
- "Community care"
- "NHS 111"

Question 3 - Thinking of your experience, please rate on a scale of 1-10 how involved you felt during the session?

Answers	Count	Percentage
1 = Not involved at all	6	11%
2	3	6%
3	4	8%
4	4	8%
5	2	4%
6	7	13%
7	5	9%
8	8	15%
9	8	15%
10 = Very involved	6	11%
<i>Answered question</i>		53
<i>Skipped question</i>		47

On average, respondents rated their experience as a 6 (slightly involved). The majority of respondents rated their experience either 8 or 9 (8 / 22%).

Question 4 - Please explain your answer to Question 3 (How involved you felt during the session?)

52 people provided an explanation. Of the comments that were received, 18 were positive, 25 were negative, 6 gave a neutral/mixed response and 3 people provided a comment that did not answer the question.

The responses are summarised below:

Positive

Of those who stated that they felt involved in their health or care experience, the key themes were:

- Felt involved in the discussion/were asked questions
- Felt listened to
- Had a good experience of accessing care/support
- Good communication
- Had their questions answered and/or explanations given
- The professional had taken the time to familiarise themselves with the patient's history/details
- Experienced joined up care
- Were updated throughout their appointment/experience
- Were shown empathy
- Were shown compassion
- Were dealt with in a caring way
- Dealt with in a timely manner
- Felt involved in the decisions about their care

Examples of positive verbatim comments:

“Discussion about how I thought my general health was at present after reducing medication. GP listened, asked questions and was interested to hear about my management of my illness.”

“Nurse knew all my details, dealt in a very caring professional way.

“Throughout a recent procedure I felt very involved as I was kept updated throughout, constantly asked how I was feeling, and the nurses kept me chatting through”

“Listened as well as allowed me to relay my concerns fully without interruption. If there was opportunity for the clinician to see and discuss the recordings of the specific issues that were of concern to me at the time.”

Negative

The key themes from who told us they had a negative and/or poor experience of being involved with their health or care appointment, were:

- Made to feel bad about their own personal circumstances
- Poor service / experience
- Felt their needs were ignored
- Had accessibility issues
- Preferred a different mode of appointment (i.e. Face-to-face)
- Did not feel involved in the discussions about their own care
- Were not involved in the discussions
- COVID-19 restrictions impacted their experience
- Lack of empathy
- Felt rushed
- Felt ignored / not listened to
- Long waiting times
- No explanations given
- Equality and diversity issues
- Felt patronised
- Referrals / appointments not made (people dropped off waiting lists)
- Delays in appointment / treatment
- Patient or family had to arrange / chase appointment and/or treatment
- Felt they were put in anxiety / stress inducing situations

Examples of negative verbatim comments:

“Trying to explain one’s symptoms via telephone very difficult. I am a retired health professional and found it a problem.”

“Lack of empathy and compassion towards my individual circumstance. Difficult to receive examination during Covid restrictions and also a delay in receiving a steroid injection.”

“I was talked at, rather than being involved in a conversation. A suggestion was made to encourage self-help (exercise); the suggestion was based on ignorance of my illness (M.E.) and ignorance of my locality ('Sit on a bench every 20 yards' - not a bench within miles.) and would have made my condition worse if I had agreed. The doctor sounded very tired (I sympathise) but I would have preferred to be asked what would help rather than being told incorrect information.”

“GP - too rushed on phone and better listening skills.”

Question 5 - On a scale of 1-10, how much do you feel that your needs and priorities were listened to?

Answers	Count	Percentage
1 = Not listened to at all	9	17%
2	0	0
3	4	8%
4	5	10%
5	4	8%
6	3	6%
7	6	12%
8	7	13%
9	7	13%
10 = Completely listened to	7	13%
Answered question		52
Skipped question		48

On average, respondents rated their needs and priorities being listened to as a 6 (slightly listened to). Most of the respondents gave a score between 8 – 10 (7 / 13%).

Question 6 – Please explain your answer to Question 5 (How much do you feel that your needs and priorities were listened to?)

52 people provided an explanation. Of the comments that were received, 19 were positive, 23 were negative, 3 gave a neutral/mixed response and 7 people provided a comment that did not answer the question.

The responses are summarised below:

Positive

The key themes of those who stated that they had a positive experience of their needs and priorities been being listened too, were:

- Felt their questions had been answered
- Caring and professional interaction with staff
- Clear explanations were given
- Clinician understood their health needs and were able to advise appropriately
- Received continued support after their appointment / treatment
- Positive experience of their appointment / treatment
- Felt appropriate discussions had been had
- Felt appropriate treatment had been received
- Were involved in the discussions about their care
- Felt they were listened to
- Felt understood by the staff they were interacting with
- The needs of the individual were focused on
- Given the limitations of pandemic, felt that the clinician had appropriately familiarized themselves with the patient's history / notes
- Positive interactions with clinicians
- Were involved in the choices about their own care
- Positive experience of using technology
- Had direction on where to get additional information
- Felt they are referred appropriately for additional support

Examples of positive verbatim comments:

“Asked me what was important and took notice of what I said. Listened to my views.”

“Checking in with you regularly, reassuring you, letting you know what to do if you feel worse.”

“The GP did focus fully on my physical and emotional needs with compassionate caring and professionalism.”

“Always listened/treatments explained, and good thought and consideration given to the health and wellbeing of the person I represent.”

Negative

The key themes from who told us they had a negative and/or poor experience of their needs or priorities being listened to, were:

- Received impersonal care
- Had their appointment cancelled
- Did not feel their condition was understood by the person providing support
- Did not feel listened to
- Were not asked any questions
- Did not think that the appropriate actions were taken at the time of their care
- Felt they did not receive the appropriate treatment
- Did not feel understood
- Did not regard the patient's own lived experience of their own condition
- Felt unsupported
- Felt they were ignored
- Had to prompt the clinician for advice and support
- Thought there was a lack of action taken at the time
- Did not feel that their needs were being met
- Felt patronised
- Negative interaction with reception staff / triage
- Did not like the mode of appointment they were offered and/or received
- Wanted more practical advice and support
- Wanted more proactive care
- Were not involved in discussions about their own care and/or treatment
- Poor communications
- Found staff to be racist
- Felt spoken at, instead of to
- Unable to make contact with staff in a reasonable amount of time
- Wanted more information than was received

Examples of the negative verbatim comments received:

“No one recognise my needs. I needed someone to visit me to see my needs.”

“The appointment was cancelled without explanation or the offer of another one.”

“It was spoken as matter of fact, no discussion about when things go wrong, and possible long term affects good and bad. Actually, go through things without me prompting, it is a lot to get in to a 15 mins appointment. I forgot to ask some things and the opportunity is lost.”

“The initial call handler clearly did not understand what she was asking of me or the condition I was reporting. It was necessary to insist on speaking to someone else for my condition to be understood and dealt with appropriately.”

Question 7 – On a scale of 1-10, how easy was it for you to ask all the questions you wanted to ask?

Answers	Count	Percentage
1 = Very difficult, I could not ask any questions	9	17%
2	5	9%
3	3	6%
4	2	4%
5	3	6%
6	3	6%
7	4	8%
8	11	21%
9	6	11%
10 = Very easy, I was able to ask all my questions	7	13%
Answered question		53
Skipped question		47

On average, respondents rated their ability to ask questions as a 6 (slightly listened to). The majority of respondents rated their experience of being able to ask all the questions that they wanted, as an 8 (11 / 22%). Notably, there was a high proportion of people (9 / 17%) who rated their experience as a 1 (Very difficult, I could not ask any questions).

Question 8 – Please explain your answer to Question 7 (How easy was it for you to ask all the questions you wanted to ask?)

50 people provided an explanation. Of the comments that were received, 15 were positive, 22 were negative, 8 gave a neutral / mixed response and 5 people provided a comment that did not answer the question.

The responses are summarised below:

Positive

The key themes from those who stated that they had a positive experience of being able to ask all the questions they had wanted during their experience, were:

- Given the opportunity to ask questions freely
- Felt listened to
- Had enough time to ask questions
- Staff were friendly
- Good experience
- Given a summary of any information
- Had prepared questions prior to the appointment
- Staff were open and approachable

Examples of positive verbatim comments:

“Has treated me for over ten years, knows me well and was encouraged to hear of my achievements”

“I was confident to ask questions and had prepared them prior to the appointment.”

“Invited me to participate in the ongoing examination of my partner - a home visit - giving me the opportunity to question the diagnosis.”

“The GP had an open approachable manner with excellent rapport skills which made it very easy to communicate with her clear questions.”

Negative

The key themes from who told us they had a negative and/or poor experience of being able to ask questions, were:

- Not given the opportunity to ask questions
- Time constraints and / or pressures prevented them from being able to ask
- Didn't know what questions to ask

- Mode of appointment / intervention prevented the ability to ask questions
- Unable to ask informed questions, due to the individual lacking initial and/or background information
- Felt rushed by the member of staff
- Were passed onto someone else
- Poor experience of triage / reception staff
- Felt able to ask questions, but were not given any answers
- Did not feel supported
- Felt they would have benefited from being checked up on and encouraged
- Unable to ask questions, as the member staff didn't know enough about them

Examples of negative verbatim comments:

“I don’t really have a roadmap for what is possible with diabetes care, I am living from blood test to blood test and one annual review to the next. I feel a little blind regarding what I could or should expect for future care. So, whilst I feel like the nurse wants me to be in control, I don’t think I have the information to do so.”

“I didn't know what questions to ask to get help.”

“Blocked by receptionist until I suggested it was life threatening.”

“No problem with asking questions just not very helpful responses.”

Question 9 – On a scale of 1-10, how well did you understand the options available to you about your care?

Answers	Count	Percentage
1 = I did not understand	6	12%
2	3	6%
3	3	6%
4	1	2%
5	2	4%
6	5	10%
7	5	10%
8	8	15%
9	6	12%
10 = Completely understood	13	25%
<i>Answered question</i>		52
<i>Skipped question</i>		48

On average, respondents rated how well they understood the options being offered to them about their care as a 7 (slightly understood). A quarter of the respondents this as a 10 (13 / 25%).

Question 10 – Please explain your answer to Question 9 (How well did you understand the options available to you about your care?)

45 people provided an explanation about how well they understood the options available to them about their care. Of the comments that were received, 14 were positive, 23 were negative, 5 gave a neutral / mixed response and 3 people provided a comment that did not answer the question.

The responses are summarised below:

Positive

The key themes from those who stated that they had a positive experience, were:

- Options were fully explained
- The options were understood by the patient
- Clear and understandable choices were given
- The patient was included in the decision making

Examples of positive verbatim comments:

“Dr said what they thought best options were, then asked what I felt was most appropriate.”

“A prescription for the change prescription sent to the chemist and subsequent collection same day. Instructions for face to face conversation and shared decision on care plan.”

“Dr was excellent at explaining my options and checked I understood the Triage process.”

“Gave time and revisited the options as the treatment proceeded.”

Negative

The key themes from who told us they had a negative and/or poor experiences, were:

- No options were given
- The options were not discussed
- Not given the opportunity to ask questions
- Not enough information given to make an informed choice
- The respondent was too unwell to digest the information being given at the time
- Did not like the mode of appointment offered
- Did not agree with what was being offered.

Examples of negative verbatim comments:

“The options were not available, not made available, actively obstructed. I perfectly well understood what should have been available.”

“When unwell I couldn’t take in information and options.”

“There are no options. It’s one operation and that’s it. No mention of if things go wrong. I will be bruised afterwards and that’s just the way it is.”

“I don’t know what my options are. I take drops for my eye condition, but this is the first proper appointment I have had for two years.”

Question 11 – On a scale of 1-10, how involved were you in making a plan about the next steps in your care?

Answers	Count	Percentage
1 = Not involved at all	15	29%
2	1	2%
3	3	6%
4	1	2%
5	2	4%
6	6	12%
7	3	6%
8	7	13%
9	4	8%
10 = Very involved	10	19%
<i>Answered question</i>		52
<i>Skipped question</i>		48

On average, respondents rated how involved they felt in making a plan about the next steps in their care, as a 6 (slightly involved). The highest proportion of respondents (15 / 29%) rated their experience of being involved in the planning of the next stages of their care, as a 1 (Not involved at all).

Question 12 – Please explain your answer to Question 11 (How involved were you in making a plan about the next steps in your care?)

44 people provided an explanation. Of the comments that were received, 18 expressed that they felt involved, 19 felt that they were not involved, 6 gave a neutral/mixed response and 0 provided a comment that did not answer the question.

The responses are summarised below:

Positive

The key themes from those who stated that they had a positive experience of being involved in planning the next steps in their care, were:

- Knew what was required and/or the next steps
- Knew what was expected, but would have liked a follow up appointment
- Full explanations were given
- Were confident in finding the information they needed themselves
- Had their next appointment date already booked in
- Were given additional information

Examples of positive verbatim comments:

“Yes, understood what my GP was going to do next and also agreed my next steps. I didn’t need anything written down at this point.”

“I had an agreed outcome and was aware of how to proceed.”

“It was quite clear what I should do and also the action to take if things were to go wrong.”

“Complete explanations were given which was consistent across the Team.”

Negative

The key themes from those who told us they had a negative and/or poor experience of being involved in the planning of the next steps in their care, were:

- Did not know what to expect next
- Was not offered any other support
- Felt they were being ‘passed around’ by staff
- Poor staff communication
- Patient was required to arrange the next steps in their own care themselves
- Poor experience of reception / triage staff

- Wanted advice to have been written down to take away after appointment/experience
- Had a poor experience of overall care
- Did not feel involved

Examples of negative verbatim

“There was no plan, except that blood tests would be carried out - where? by whom? when? - no information, and the tests were not done until I eventually had to take the initiative and contact the medical centre (no specific doctor allocated to my care).”

“No knowledge what I could do next. It took until October that the Surgery did my Respect form and that was on my hospital discharge notes from May 2020!”

“It would have been helpful to have the technical things written down before leaving appointment.”

“I don’t think it has been decided what the next step is. Nurse said wait and see.”

Section B – After the experience

Question 13 – On a scale of 1 – 10, how well did professionals or services support you to manage your own health and wellbeing by yourself / at home?

Answers	Count	Percentage
1 = Not supported at all	12	25%
2	3	6%
3	3	6%
4	3	6%
5	5	10%
6	4	8%
7	2	4%
8	7	15%
9	5	10%
10 = Very supported	4	8%
<i>Answered question</i>		48
<i>Skipped question</i>		52

On average, respondents rated how well the professionals or services supported them to manage their own health and wellbeing by themselves / at home, as a 5 (slightly not supported). The majority of respondents (12 / 25%) rated their experience as a 1 (Not supported at all).

Question 14 – Please explain your answer to Question 13 (How well did professionals or services support you to manage your own health and wellbeing by yourself / at home?)

40 people provided an explanation. Of the comments that were received, 9 people had a positive experience, 21 had a negative experience, 9 gave a neutral/mixed response and 1 person provided a comment that did not answer the question.

The responses are summarised below:

Positive

The key themes from those who stated that they had a positive experience, were:

- Support was given
- Clear explanations given
- The GP understood the patient's needs
- The patient was recommended / signposted to other resources
- The patient was followed up

Examples of positive verbatim comments:

“I advocate and research myself and my doctor is very supportive.”

“GP understood I was active and could use my hand splint where I had to use my right hand. She also checked I was using analgesics appropriately.”

“Complete support given for the whole journey.”

“Gave me some recommendations for reading.”

Negative

The key themes from who told us they had a negative and/or poor experience, were:

- Poor service received
- No additional support was given
- Lack of help and/or support
- Not given enough information to make an informed choice
- Felt patronised
- Information given was not clear and led to confusion
- Did not think the information given was accessible
- Information given was not clear and caused confusion

Examples of negative verbatim comments:

“There was a complete lack of help.”

“I had no help or care once I was discharged from Hospital in May 2021.”

“Try this medicine and come back & tell us if it works. How as a layman am I supposed to know if my treatment is getting better? Am I getting better or worse because of or in spite of the medicine? I am not in a position to measure the changes.”

“I was signposted to another NHS trust website for exercises. The leaflet was not easy to follow. When I finally had a face to face with a physio, they struggled to interpret two of the exercises. For elderly and vulnerable patients this form of information giving would not work for them. Maybe video recordings could be provided to patients for this who can access and use technology. I feel too many assumptions have been made that all in society can access services via technology which is simply not the case. Therefore, meaning the NHS service is not inclusive and accessible to all.”

Question 15 – On a scale of 1 – 10, how confident did you feel to about where to go to ask questions or seek support after your appointment?

Answers	Count	Percentage
1 = Not confident at all	7	15%
2	4	8%
3	3	6%
4	0	0
5	4	8%
6	4	8%
7	2	4%
8	5	10%
9	9	19%
10 = Very confident	10	21%
<i>Answered question</i>		48
<i>Skipped question</i>		52

On average, respondents rated how confident they felt about where to go to ask questions or seek support after their appointment, as a 6 (slightly confident). The majority of respondents (10 / 21%) said that they felt “very confident”.

Question 16 – Please explain your answer to Question 15 (How confident did you feel to about where to go to ask questions or seek support after your appointment?)

40 people provided an explanation. Of the comments that were received, 18 people had a positive experience, 17 had a negative experience, 1 gave a neutral/mixed response and 4 people provided a comment that did not answer the question.

The responses are summarised below:

Positive

The key themes from those who stated that they had a positive experience, were:

- They knew where to go to get support or ask questions (Examples given; GP, Doctor's surgery, Receptionist, Online, Electronic patient records, Website, NHS/GP Systems, Follow-up call, Was given individual team's / department's contact information, Nurse specialist.)

Examples of positive verbatim comments:

"Contacted surgery to clarify a particular issue, responsive and helpful."

"My GP is usually my first place with non-emergency medical problems."

"The nurse told me about the Glaucoma website which might be helpful to me."

"I was given a number to ring if I needed further help."

Negative

The key themes from who told us they had a negative and/or poor experience, were:

- Did not know where to ask questions / get support
- Poor interactions in the past have prevented and / or put off the person from gaining future support / advice
- Were left without any information
- Believe private healthcare is the only option for themselves going forward
- Did not know where to go / who to ask
- Reception / triage have prevented the patient from gaining further support
- Lack of ownership from the health or care professionals
- No defined route

Examples of negative verbatim comments:

“I am used to advocating for myself, but it is still hard when you don’t feel well.”

“Difficult getting past reception. Some of the GP teamwork part time so difficult to get the same person. Don't think there was a way to ask questions afterwards except by fighting past the reception and pretending to be urgent.”

“No one helped me contact the right people and I was on my own.”

“There is no designated contact number at the hospital, and I presume that I would have to get in touch via my GP. There is a phone number (answer phone). I would prefer a defined route direct to the hospital.”

Question 17 – On scale of 1-10, how easy do you find it to access useful support and information by yourself?

Answers	Count	Percentage
1 = Very difficult	8	17%
2	0	0
3	2	4%
4	4	9%
5	3	6%
6	1	2%
7	4	9%
8	10	21%
9	7	15%
10 = Very easy	8	17%
<i>Answered question</i>		47
<i>Skipped question</i>		53

On average, respondents rated how easy they found it to access useful support and information by themselves, as a 6 (slightly confident). The highest proportion of respondents rated their experience, as an 8 (22%).

Question 18 – Please explain your answer to Question 17 (How easy do you find it to access useful support and information by yourself?)

38 people provided an answer. Of the comments that were received, 11 people had a positive experience, 18 had a negative experience, 4 gave a neutral / mixed response and 5 people provided a comment that did not answer the question.

The responses are summarised below:

Positive

The key themes from those who stated that they had a positive experience, were:

- Knew where to go to access support and information themselves
- Were able to find information themselves
- Were confident to manage their own condition

Examples of positive verbatim comments:

“It is easy for my heart condition to access information. Not always from the GP as sometimes you feel it is a trivial question, but I have someone else I can ask.”

“Used internet and GP.”

“I’m reasonably confident on using the internet so I search for sources. I also have a good relationship with two Nurse Specialists for support via mobile texting or email. The local Community transport system was severely compromised during the pandemic. I’m very happy to receive emails or texts regarding support.”

“I accessed national helpline when very distressed with pain and local wellbeing group in Community to help me continue volunteering with lighter work and social contact.”

Negative

The key themes from who told us they had a negative and/or poor experiences, were:

- Were signposted to services they could not access
- Did not know where to go to access support and information themselves
- Felt they had to pay privately for the help and support they needed
- Found information to be inaccessible to those with a visual impairment
- Felt they had a lack of support / information
- Had to do research on the internet themselves
- Could not find the support / information they needed online

- Felt better advice and support should have been given to them during their appointment
- Felt they had been passed on to someone else or other organisation
- Did not think the person / organisation they had been passed on to were helpful
- Felt like it was a 'battle' against the 'system' to get support / help

Examples of negative verbatim

"I find web-based information on lifestyle and medication and explanations of test results regarding diabetes on the diabetes UK website. Accessing community support, just because I have a LTC doesn't mean I would want to be part of a group with other people who have it, it's probably the last thing I would be interested in. Other involvement in community activity around exercise or lifestyle would be appropriate however as mentioned before I have zero time and energy for this, work full time, single parent of 3 teenagers."

"Being severely visually impaired I do find it difficult to access in accessible websites when looking for information. I can't read print. Leaflets are no good to me. I would like to receive my appointments and correspondence by email."

"Google good. No other way unless go to A&E. No support offered & phone always a battle which puts you off."

"Passing responsibility to a charity (or other non-statutory organisation) is to abdicate responsibility. Charities have nothing to offer (why should they?) apart from 'tea and sympathy', which does nothing to reduce the burden of illness, or to make life less unbearable. Never mind information about support - for goodness' sake provide support!?"

Question 19 – Staying involved in the development of the Personalised Care Strategy.

The respondents were asked if would like to stay involved in the development of the Personalised Care Strategy.

21 respondents provided their contact details. This information is securely stored by the CCG and has been omitted from this report.

Demographic Questions

Question 20 - What is the first part of your postcode?

Answers	Count	Percentage
B60	1	2%
B61	2	4%
B96	1	2%
B97	3	7%
B98	3	7%
DY10	3	7%
DY11	1	2%
DY12	1	2%
DY13	1	2%
DY9	1	2%
GL	1	2%
HR1	2	4%
HR2	2	4%
HR4	2	4%
HR6	1	2%
HR7	1	2%
WR10	1	2%
WR11	1	2%
WR13	1	2%
WR14	3	7%
WR2	4	9%
WR3	1	2%
WR4	2	4%
WR5	4	9%
WR9	3	7%
Answered question		46
Skipped question		54

80% (37) of respondents were from Worcestershire. The most active postcode areas were WR2 (4 / 9%) and WR5 (4 / 9%).

Question 21 - Please tell us your age

Answers	Count	Percentage
Under 18	0	0%
18 – 24	0	0%
25 – 34	0	0%
35 – 44	2	5%
45 – 54	3	7%
55 - 64	10	23%
65 - 74	19	43%
75 – 84	8	18%
85+	2	5%
Prefer not to say		
Answered question		159
Skipped question		9

The respondents were from a mix of age groups, with those aged between 65 – 74 making up the largest group (43% / 19). There was no representation from people aged 34 and below.

Question 22 - Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

Answers	Count	Percentage
Yes, limited a lot	13	28%
Yes, limited a little	16	35%
No	16	35%
Prefer not to say	1	2%
Answered question		46
Skipped question		54

35% (16) of respondents reported that their day-to-day activities were limited a little due to a health problem or disability.

Question 23 - Do you consider yourself to have a disability?

The Equality Act 2010 states a person has a disability if they have a physical or mental impairment which has a long term (12 month period or longer) or substantial adverse effects on their ability to carry out day to day activities).

Answers	Count	Percentage
Physical disability	13	32%
Sensory disability e.g. Deaf, hard of hearing, Blind, visually impaired	3	7%
Mental health need	8	20%
Learning disability or difficulty	1	2%
Long term illness	13	32%
Prefer not to say	3	7%
Other / Please describe	27	66%
Answered question		41
Skipped question		59

**Respondents were able to give more than one answer.*

38 (93%) respondents who completed this question, stated that they had a disability based on the definition given in the Equality Act 2010 (above). The most common answer was "Other" (27 / 66%) given by those who reported to have a disability. 59 people (59% of the overall number of respondents) skipped this question.

Upon completion of the evaluation, it was observed that there was no answer option for respondents to record if they did 'not' consider themselves to have a disability, other than to select 'other' or to skip the question. This potentially could have caused confusion for some respondents when answering this question, and this question will be revised for future surveys. Due to this omission, it is recommended that inferences or conclusions are not drawn from this demographic question

Question 24 – Do you identify as?

Answers	Count	Percentage
Male	18	38%
Female	27	57%
Transgender male	0	0
Transgender female	0	0
Non-binary	0	0
Prefer not to say	4	2%
Prefer to delf describe	0	0
Answered question		47
Skipped question		53

The majority of respondents (27 / 57%) identified themselves as female.

Question 25 – Gender Reassignment

Answers	Count	Percentage
Yes	0	0
No	42	95%
Prefer not to say	2	5%
Answered question		44
Skipped question		56

The majority of respondents (42 / 95%) reported to have not gone through any part of the gender reassignment process.

Question 26 - What is your sexual orientation?

Answers	Count	Percentage
Heterosexual (people of the opposite sex)	39	85%
Lesbian (both female)	1	2%
Gay (both men)	0	0
Bisexual (people of either sex)	2	4%
Prefer not to say	4	9%
Other (please specify)	0	0
Answered question		46
Skipped question		54

Most respondents (85% / 39) stated they were heterosexual.

Question 27 – What is your ethnic group or background?

Answers	Count	Percentage
Asian/Asian British	0	0
Asian/Asian British - Indian	0	0
Asian/Asian British - Pakistani	0	0
Asian/Asian British - Bangladeshi	0	0
Asian/Asian British - Chinese	0	0
Any other Asian background, please describe	0	0
Black/ African/Caribbean/Black British	0	0
Black/ African/Caribbean/Black British - African	0	0
Black/ African/Caribbean/Black British - Caribbean	1	2%
Any other Black/African/Caribbean background, please describe	0	0
Mixed/Multiple ethnic groups	0	0
Mixed/Multiple ethnic groups - White and Black Caribbean	0	0
Mixed/Multiple ethnic groups - White and Black African	0	0
Mixed/Multiple ethnic groups - White and Asian	0	0
Any other Mixed/Multiple ethnic background, please describe	0	0
White	8	17%
White - English/Welsh/Scottish/Northern Irish/British	34	74%
White - Irish	0	0
White - Gypsy or Irish Traveller	0	0
Any other White background, please describe	0	0
Other ethnic group - Arab	0	0
Prefer not to say	3	7%
Other (please specify)	0	0
Answered question		46
Skipped question		54

74% (34) of respondents reported that their ethnic group or background was “White - English/Welsh/Scottish/Northern Irish/British”.

Question 28 - Do you care for someone?

Answers	Count	Percentage
Yes – Care for a young person	4	9%
Yes – Care for adult(s) aged 25 – 49 years	2	4%
Yes – Care for an older person aged over 50 years of age	9	20%
No	30	65%
Prefer not to say	3	7%
Answered question		46
Skipped question		54

33% (15) of respondents reported that they cared for someone. The majority (30 / 65%) of respondents advised that they were not carers.

Question 29 – Have you recently given birth or have become a parent to a newborn baby (within the last 26 weeks)?

Answers	Count	Percentage
Yes	0	0
No	43	96%
Prefer not to say	2	4%
<i>Answered question</i>		45
<i>Skipped question</i>		55

96% (43) had not given birth or had become a parent to newborn baby within the past 26 weeks.

Recommendations

We would make the following recommendations:

1. **Incorporate the responses and feedback into new Personalised Care Strategy.**
2. **Continued Engagement** – As part of the new Personalised Care Strategy, ensure that patients, carers, staff and partners can be continually engaged and give their experiences. Allow for regular sense checking, feedback and the opportunity to hear people's stories.

Appendix

Appendix 1 – Survey Distribution List

Person or Group	Information Sent
Herefordshire and Worcestershire Involvement Network (HWIN)	Survey Link and Information
Herefordshire and Worcestershire Patient Participation Group (PPG) Network	Survey Link and Information
NHS Engagement Officers Network (all patient engagement and patient experience leads within the Herefordshire and Worcestershire Integrated Care System area)	Survey Link and Information
Herefordshire and Worcestershire CCG Social Media	Survey Link and Information
Healthwatch Herefordshire	Survey Link and Information
Healthwatch Worcestershire	Survey Link and Information
ICS Personalised Care Collaborative	Item on the agenda
Public Health teams in Worcestershire and Herefordshire	Survey Link and Information
Young People's Engagement Network Group (YENG) (membership is made up from voluntary and community sector organisations, public sector and private sector)	Survey Link and Information
Herefordshire and Worcestershire CCG website	Survey Link and Information
Member Practice Update (MPU) Newsletter (all GP survey members practices in Herefordshire and Worcestershire)	Survey Link and Information
TeamNet (all clinical and administrative primary care staff in Herefordshire and Worcestershire)	Survey Link and Information