



Waiting for Hospital Care

How people feel about waiting to access hospital care: Findings from a patient survey

A partnership report - Healthwatch Hampshire, Healthwatch Isle of Wight, Healthwatch Southampton & Healthwatch Portsmouth

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Context

The COVID-19 pandemic resulted in many people having their operations, treatment and appointments cancelled or delayed.

The NHS had to postpone non-urgent elective care treatment when the pandemic hit, freeing up inpatient and critical care capacity. While this helped medical staff respond to the crisis, it has resulted in a huge backlog of people waiting for treatment.

The latest data shows that the number of people waiting for routine operations and procedures in England is at its highest level since 2007 – currently over 6 million.

The impact of delayed treatment can be huge, potentially leaving people in pain and affecting both their physical and mental health. It can even stop people working and performing day-to-day tasks, such as cleaning, shopping and caring for others.

It is essential that while people wait for treatment, they get support to manage their health and wellbeing in a way that is best for them. If someone needs hospital treatment, they should be receiving advice and information from the NHS about how to look after their health while they wait. (Ref: The NHS delivery plan for tackling the backlog¹). They should be kept informed about the dates of their treatment and where they are on the waiting list.

The four Healthwatch across the Hampshire and Isle of Wight Integrated Care System (ICS) undertook a survey between May 2022 and August 2022 to provide insight to enable services to understand the local experience of waiting, to improve effective communication with those who are waiting, and reduce the potential for harm or deterioration while people are waiting.

¹ <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2022/02/C1466-delivery-plan-for-tackling-the-covid-19-backlog-of-elective-care.pdf>

Research Objectives

Understand the experience of waiting for hospital treatment

- Attitudes to waiting, and the impact of waiting.
- Information and advice received while waiting.
- Advice about health and care, and advice on waiting times.
- People's sources for advice and guidance while waiting.
- Whether people would be willing to be treated at a potential new hub in Winchester.

Method

This report details the responses gathered from the Healthwatch Hampshire, Healthwatch IOW, Healthwatch Southampton and Healthwatch Portsmouth areas. The survey was in online format only. A total of **2114** validated responses were received (note only fully completed responses have been included):

Healthwatch area	Number of validated responses received
Healthwatch Hampshire	1116
Healthwatch Southampton	780
Healthwatch IOW	200
Healthwatch Portsmouth	18

The same work was undertaken for the Frimley ICS area (see separate report) by Healthwatch Slough, Healthwatch Windsor/Ascot/M Maidenhead, Healthwatch Bracknell Forest, Healthwatch Hampshire and Healthwatch Surrey (who reported separately). All reports have been produced in the same format to provide a consistent approach. We wish to acknowledge the work of Healthwatch Surrey in producing that format, which we have followed here (note much of the

Context, Method, Scope etc will be duplicated in both reports with amendments where appropriate for local considerations and survey question adjustments).

In addition to the questions patients were asked for the Frimley ICS survey, the survey for Hampshire & IOW ICS patients included questions relating to whether people would be willing to travel for treatment to a hospital in the Winchester area. In order to help provide context for these additional questions, this report details findings separately for each of the 4 areas.

Scope, risks and limitations

The respondents in this survey were self-selected; the survey does not deliver a representative sample of people in the Hampshire & IOW ICS area waiting for treatment, and it should not be used as a quantitative record of experience. Inevitably, we hear more from those with a bad experience to share than those whose experience was as expected or better than expected.

What the survey does do is shine a light on a range of experiences of waiting. There is a particular focus on opportunities to improve, but we also recognise good practice. Our aim is that our findings and recommendations are used as insight to enrich strategy and inspire opportunities to improve systems.

Summary

The experience of waiting

The focus of the survey was on information needed and received by those waiting for hospital treatment (or had waited for treatment in the past year). Work by Healthwatch England and The King's Fund shines more light on the day-to-day realities of waiting for treatment²

We found:

- Any need to wait is worrying for many patients.
- Uncertainty about the length of wait is a major concern.
- Even those waiting less than 2 months felt generally negative.
- The longer the wait the more detrimental effect it has on people's health and/or wellbeing and mental health, lifestyle and family life, pain levels, mobility and fears of worsening conditions. People talked about life "being on hold".
- People told us they had used NHS111 and A&E services more frequently due to having to wait for treatment and worsening health.

Feedback about being offered the Winchester option:

- As would be expected, people living closer to Winchester would be happy to attend their appointment/receive treatment there.
- Although many people advised they would be willing to travel if they could have their treatment/appointment sooner there were also many concerns:
 - There were concerns from Hampshire and IOW respondents over the distance to travel to a Winchester hospital, travel costs and issues with delayed and cancelled ferry crossings.
 - Concerns over the lack of public transport/public transport timings, car parking and travel costs.
 - Issues around work commitments due to longer travel times.
 - Concerns about travelling long distances when unwell/receiving treatment.
 - Concerns over caring responsibilities if having to travel further.

² <https://www.healthwatch.co.uk/news/2021-09-27/people-living-poorest-areas-waiting-longer-hospital-treatment>

- Concerns over vulnerable people (older/dementia/frail etc) having to travel further.
- Environmental concerns encouraging more travel.
- Concerns over the ability of family/carers etc to visit patients in hospital if a long way from home.
- Fears of being “sent to the bottom of the list” if an option to attend a Winchester venue is turned down by the patient.

Information, advice and support

- A majority of people felt they had NOT been given information and/or support by either their hospital or GP to help them manage their condition whilst waiting (note – given the wide range of conditions and wait times it’s not possible to know what information or support respondents should have been given).
- A majority of people had NOT been given details of someone to contact if their condition had got worse whilst waiting for treatment.
- Many stated they had NOT been given advice or information on how to improve their health while waiting.

A main theme arising from the feedback is that people want and need more detailed information, and frequent updates around waiting times and changes to planned treatment. This allows them the ability to plan their lives better and provides an assurance that they are not forgotten (words that are frequently used in the feedback).

We acknowledge that the NHS My Planned Care Patient Digital Platform was only launched in February 2022 and therefore it is possible that not enough time had elapsed for Trusts to provide patients that completed this survey (during May to August) with the relevant information or being “in the system” already, communication about the platform did not reach them as it may for newly referred patients. It is hoped that this platform will help alleviate some of the waiting time uncertainties expressed by patients.

And finally, although many people acknowledged and expressed understanding for the issues and pressures that the NHS has faced during Covid, and continues to face, throughout the feedback the words “desperate”, “frustrated”, “sad” and “disappointed” were repeated many times in responses received.

Recommendations

We recognise and understand the current pressures on the NHS and acknowledge that providers are already doing their utmost to minimise waiting times for patients. We also appreciate that the current situation is not going to be resolved quickly.

With this in mind, and based on the feedback received, we therefore make only 3 recommendations. 1 and 2 relate to how people should be actively supported to manage their condition to reduce anxiety and stress whilst waiting for treatment.

- 1. Review how patients can be provided with the information/advice/contacts and signposting they need to stay well, manage their condition and prevent avoidable deterioration while waiting for treatment, whether this comes from the hospital or via primary care.**
 - a. Automated services such as texts and emails should be considered.**
 - b. Further develop the information available on the NHS My Planned Care platform and actively promote it.**

- 2. In order to improve trust and communication, and to reduce anxiety and stress, patients should be regularly informed (ideally every 12 weeks minimum) when their appointment is due or likely to be due. Reasons for delays should be made transparent.**

- 3. Any decisions to offer alternative services for the IOW should take into consideration the unique issues around transport and travel.**

Demographics

(Of those that responded to these questions)

Note due to low response rate for Portsmouth, results will not be particularly meaningful – but for information purposes the results are shown below in terms of numbers only.

	Survey completed on behalf of		
	Self	Another adult	Child under 18
Hampshire	96%	3%	1%
Southampton	96%	3%	1%
IOW	88%	11%	1%
Portsmouth	17	1	0

	Age (of respondent or person survey completed on behalf of)					
	25 or under	26-49	50-64	65-79	80+	NA/Prefer not to say
Hampshire	1%	14%	28%	46%	8%	3%
Southampton	3%	20%	31%	40%	5%	1%
IOW	2%	16%	25%	42%	13%	2%
Portsmouth	0	1	9	8	0	0

	Gender		
	Male	Female	Other/Prefer Not to say
Hampshire	43%	53%	4%
Southampton	37%	61%	2%
IOW	34%	63%	3%
Portsmouth	5	12	1

	Ethnicity			
	White British	White Any Other	Other	Prefer Not to say
Hampshire	88%	4%	3%	5%
Southampton	90%	2%	6%	2%
IOW	92%	3%	0%	5%
Portsmouth	14	1	2	1

	Respondents who:	
	Are an unpaid carer	Have a disability or long-term health condition
Hampshire	9%	45%
Southampton	5%	37%
IOW	13%	41%
Portsmouth	1	9

	Type of treatment					
	Pre-op	Day Surgery	Op with overnight	Ongoing treatment	Rehab	Other
Hampshire	6%	28%	21%	19%	2%	24%
Southampton	6%	31%	22%	21%	2%	18%
IOW	5%	34%	32%	9%	1%	19%
Portsmouth	1	5	5	2	0	5

	Hospital referred to (for both "still waiting for" and "already received" care)			
	Hampshire	Southampton	IOW	Portsmouth
Basingstoke & N. Hants	5%	0	0	0
Princess Anne	0	6%	0	0
Queen Alexandra	8%	0	2%	13
Royal Hants	16%	15%	0	0
Southampton General	53%	70%	4%	1
St. Mary's IOW	0	0	90%	0
Other	18%	9%	4%	4

	Percentage waiting or already received care		
	Currently waiting	Received care	NA
Hampshire	42%	39%	19%
Southampton	49%	45%	6%
IOW	63%	15%	22%
Portsmouth	12	4	2

Main Findings

The experience of waiting (of those that responded to these questions)

Length of wait – for those people who are currently still waiting

	Length of time					
	0-2 mths.	3-4 mths.	5-6 mths.	7-12 mths.	1-2 yrs.	Over 2 yrs.
Hampshire	16%	13%	8%	16%	10%	6%
Southampton	22%	9%	8%	15%	8%	6%
IOW	8%	16%	14%	20%	20%	10%
Portsmouth	1	1	1	3	2	0

Length of wait – for those who have already received treatment

	Length of time					
	0-2 mths.	3-4 mths.	5-6 mths.	7-12 mths.	1-2 yrs.	Over 2 yrs.
Hampshire	24%	10%	7%	7%	4%	3%
Southampton	26%	8%	6%	7%	5%	2%
IOW	10%	2%	4%	6%	10%	4%
Portsmouth	1	1	1	3	2	0

When asked “How do you feel about the length of time you waited/are still waiting?” the following shows the percentage of those who expressed negative feelings.

	Percentage
Hampshire	47%
Southampton	45%
IOW	73%
Portsmouth	14

Some examples of feedback:

"It is now 9 weeks since the referral letter was sent, I have had no indication as to when an appointment will be available. Meanwhile I have concerns about the possibility of losing at least a part of a limb. My mobility is severely limited".
(Hampshire – wait 0-2 months for ongoing lower limb treatment).

"Very dissatisfied. I was referred to the dermatologists at the HHFT consultant dermatologist's suggestion, following a request from my GP for advice and guidance in August 2021. at the time, I was advised that there was a 32 week wait, but every time I call for an update, the waiting time gets longer. when I last enquired in April 2022, the waiting time had increased to 49 weeks and I am still waiting – I dread to think how much longer it has got since then. The My Planned Healthcare website states that the average waiting time at RHCH for dermatology is just 17 weeks. this is clearly incorrect. what steps do the NHS take to ensure that the information RHCH/HHFT provide on this is accurate and how are delays kept in check?" (Hampshire – wait 1-2 yrs. for dermatology diagnostics).

"Due to the pandemic previous appointments had been cancelled or changed to later dates causing extra delays. I am not as important as many other treatments and surgeries however being left in pain for a number of months did cause me to feel down". (Hampshire – wait 3-4 months for day surgery to lower limb).

"I was afraid that the condition would become catastrophic, and I'd need to be rushed off via A&E. I am my husband's primary carer, so a planned date was absolutely essential. Instead, I had to try to plan for an emergency at some unknown date – which I tried to do via Care in Southampton's online emergency planning tool. This proved very difficult and stressful – trying to patch together a network of friends, one (only) son and visiting carers to the house. I was on a priority emergency list but was told people had been on it for over a year." (Hampshire – wait 5-6 months for operation to correct broken limb).

"Resigned. I know it is not an emergency and I understand why there is a backlog/delay. When I have a particularly bad flare up (which is happening more and more) I am tempted to attend A&E although I know this will add to the backlog." (Hampshire – wait 5-6 months for gallstone removal).

"I was referred to Frimley Park Hospital February 2022 and have not got an appointment for a telephone consultation until 26th October 2022. I am extremely concerned as I have been told by my GP that I am at risk of blood clots whilst my heart is out of rhythm. I have no idea how long I have to wait to receive the treatment I need which I am finding extremely stressful." (Hampshire – wait 7-12 months for heart day surgery).

"I understand why there has been a delay and am not cross but I would like to know how much longer I have to wait, I have written and left a phone message asking for a rough idea how long I still have to wait but no one has replied. This annoys me, a brief letter in the post would not take them long to write." (Hampshire – wait 7-12 months for bladder operation).

"The additional wait aggravated the condition and caused considerable pain resulting in a visit to A&E via 111". (Portsmouth – wait 7-12 months for hernia operation).

"Very upset and disappointed. I was told in November 2020 I needed the procedure, then had to wait 6 months for a follow up appointment. I was put on the list at the end of May 2021. I had a pre-assessment at home early January this year, then after chasing a pre-assessment at St Marys at the beginning of April. I phoned the pre assessment unit this week to find out any information to be told that all the July and August lists have been cancelled!!!!" (IOW – wait 1-2 yrs. for hysterectomy).

"Agonising depressed and very lonely". (IOW – wait 1-2 yrs. for knee operation).

"I felt very anxious about the wait. My tumour had to be under 4cms to still qualify for robotic surgery. I was informed on March 23rd 2020 after a CT scan that I had a solid tumour in my left kidney so as the UK went into lockdown, I then had the worry of potential kidney cancer. I had regular CT scans to monitor the tumour growth over the next 20 months, but it wasn't until the 16th of November 2021 I had the op. This was cancelled once from 8th November 2021, so that was a worry. St Marys Hospital did the PCR test on the 13th November, but this wasn't available when I got to QA Portsmouth so had to be repeated. A further worry that they were going to send me away again. I had a pre op assessment at QA 2 weeks prior to the apt, this I had to have in person, but quite honestly my weight, height, ECG and Bloods could have easily been done on the IOW and not have made me travel all the way to QA from Ryde".
(IOW – wait 1-2 yrs. for kidney cancer operation).

"It has been too long especially that I have had several xxx episodes. The last one in February 2022 where I had four days in hospital as the gall stones had caused a blockage in my liver and I was jaundiced. Still, I've had to wait and still waiting". (IOW – wait 1-2 yrs. for gallbladder surgery).

"I'm on a lot of medication to manage my pain/discomfort whilst I'm waiting for my operation. I spend a lot of time in the a&e department getting treatment. I was told last year I would only have to wait 6-8 weeks, this April when I went to a&e I was told 4-6 weeks, I'm still waiting nearly 7 weeks later." (IOW – wait 1-2 yrs. for gall bladder surgery).

"I am frustrated by the lack of communication. The initial colonoscopy was undertaken was undertaken quickly (1st Feb) but it took over 6 weeks to receive the official letter referring me to gastroenterology. Since 14 March I have phoned numerous times but have no idea when I am likely to be invited for an appointment". (IOW – wait 3-4 months for suspected bowel disease diagnosis).

"Waiting for physio and gastroenterology for over a year, frustrated, trying to help myself at 80 years old, nobody cares". (IOW – wait 1-2 yrs.)

"I was told I likely had ovarian cancer. And I needed to go through a succession of scans (Ultrasound / CT / MRI) - and there was a 2-3 month wait for each scan. This was a very stressful time, where I had little contact with medical professionals and had to wait it out, potentially while my cancer grew". (IOW – wait 5-6 months for suspected ovarian cancer diagnosis)

"Since being put on the orthopaedic surgeon's list for shoulder and knee replacement I have heard nothing. During this time obviously the condition has become more painful and mobility more restricted. There is no indication how long the waiting list is. After receiving a letter from the NHS which gave details of a link to My Planned Care Patient Platform, I went online to find the average waiting time for orthopaedic operations at St Mary's NHS Hospital Newport. Accordingly, I found it was 19 weeks. This surprised me as the waiting time on St Mary's Orthopaedic site states 43 weeks. I then rang Mr xxx secretary who advised the waiting time at St Mary's is in fact 43 weeks". This is unacceptable. (IOW – wait 5-6 months for shoulder/knee operation).

"The worst thing about the wait is that there seems to me no information available about the timescale, which makes planning your life very difficult. I had a visit from the nurse for preparatory tests just before Easter and have heard nothing since". (IOW – wait 7-12 months for hand surgery).

"I can understand that due to Covid and bed blocking extended and lengthy waiting times have become the norm. However, after a wait of 30 weeks between GP referral and surgeon consultation and then 50 weeks until I was invited to Preassessment followed by 25 weeks before a second reassessment and Consent I've been frustrated and worried". (IOW – wait over 2 yrs. for hernia repair).

"Just would like to get the treatment over and done with so can get back to having a life. Waiting seems like it's never ending. Feels like as an elderly lady they are just waiting for her to 'drop dead' so they won't have to give her treatment." (IOW – wait 5-6 months for hip surgery).

"The whole experience caused by the Pandemic has been protracted to the extent that I wonder if the various tests prior to surgeon appointments are at all relevant now. My initial appointment with Dr xxx was Feb. 2020. Follow up tests were understandably cancelled or rearranged due to Covid. Since then, due to various non-communication issues the prospect of ever having this remedial operation has become somewhat of a dream". (IOW – wait 1-2 yrs. for thyroid surgery)

"It has also affected my ability to look after my disabled son". (IOW – wait 3-4 months for ongoing treatment, condition unknown).

"I know all medical services are busy, but I think this has created a culture where patients are expected to feel grateful for anything that is done, rather than consideration being given to what could be done relatively easily, that would make a big difference, e.g., some idea of waiting time. I think to be honest, this is information that is being actively hidden so people don't realise how dire the situation is, but we do have a right to know". (IOW – wait 7-12 months. for day surgery, condition unknown).

"I think insufficient consideration is given to the effects on your life. I have daily dizziness. I'm unable to work, unable to claim for anything. My family suffer daily. Nothing is done, you are just fobbed off. My health has deteriorated rapidly. I can't exercise, can't sleep. I'll be dead in a few years at this rate and I'm 50". (IOW – wait over 3-4 months for tinnitus treatment).

"This is devastating. My daughter who is 14, needed to remove her primary tooth has been referred by dentist for maxillofacial surgery nearly 2 years ago. Several assessments were done in UHS and finally she got an appointment in September 2021. During the appointment, my daughter was really disappointed and was in tears hearing from the consultant that it will take another three months for the procedure. After the appointment, the consultant has gone on maternity leave and when I rang the department they are apologising and saying the other consultants are only seeing their own patients and my daughter has to wait until the consultant is back which they do not know when

and even if the consultant is back they will only be working part time. The permanent tooth that has grown behind primary tooth is causing her discomfort and insult from friends. Also, the feeling that she will not have her braces done before it is too late is giving her huge stress.” (Southampton – wait 1-2 yrs. for maxillofacial surgery).

“It has made me very anxious. I have been having pleasure in my head and palpitations since then and it has reduced the quality of my life. I have called the cardiology department several times and was given an email address to send my complaint to, but I was given a wrong email address. I have been living in fear of my life and health ever since.” (Southampton – wait 7-12 months for echocardiogram).

“Frustrated that no timescales have been provided, if I was told it would be a wait of a year I would not be feeling disheartens by the NHS service. Recently I received a text to ask for a questionnaire which asked if I still wanted the treatment so I assumed the surgery would be soon but clearly not.” (Southampton – wait 1-2 yrs. For endometriosis day surgery).

“Not impressed. My referral was initially returned to my GP and had to be sent back again (2021). I've still not seen a neurologist and am extremely disabled by my condition with no neuro type support since early 2020. My appointment was due to happen in July but has been postponed again until November. My doctor is pushing for me to have my brain scanned to see if I had suffered a stroke back in 2020. Something I thought might have been more urgent than 2.5 yrs.” (Southampton – wait 1-2 yrs. for investigation into possible stroke).

“I understand the reason, but my condition gets worse. If someone just kept you informed how long await it could be, it would be helpful. Once you are told you are on the waiting list, you don't hear anything else. You wonder if you have been forgotten, as you have no one to contact, I feel frustrated.” (Southampton – wait 7-12 months for knee replacement).

“Extremely frustrated as in severe back pain. Life totally put on hold as any movement was excruciating. I would not dream of going to A&E (unlike some) as its not life threatening. I had 3 months of total inactivity with very little pain relief as previous experience following a car accident showed that I got no pain relief from several preferred medications prescribed. I take only paracetamol to take the edge off from the chronic pain in my back and shoulder brought on from the accident. I was early retired from work because of this condition. Apologies for going on a bit 😞.” (Southampton – wait 3-4 months for back pain support).

“My wife's left knee is deteriorating rapidly and causing her considerable pain at night when resting and particularly when walking with the aid of elbow crutches and wearing a knee brace. Her GP has warned her that she is likely to lose her ability to walk at all if the necessary work is not carried out soon. The original partial replacement could easily require a full one if nothing is done in the near future. Her specialist has told her doctor that the operation could take place before Christmas.” (Southampton – wait 7-12 months for knee replacement).

“When suffering and in so much chronic pain the wait seems forever. It's unbearable to live with. Can't make it ease. I don't know who to turn to to help me. To believe how much this pain hurts. Continuously.” (Southampton – wait 3-4 months for nerve treatment).

“It's Ridiculous that I've had 6/7 appointments cancelled in the last 12 months meaning I haven't seen my consultant for 13 months, my ongoing treatment isn't keeping me well but can't change treatment until I see consultant.” (Southampton – wait 7-12 months for ongoing Crohn's treatment).

“I was told in January 2022 that I would have the operation within 6 weeks. I have to ring admissions on a regular basis to try and get updates. I have had my pre op in June and told recently that I would probably have to have another pre op as his runs out in Sept. 22.” (Southampton – wait 7-12 months for thyroid operation).

“Far too long, considering surgeon has said this is urgent, and has advised us to seriously consider private treatment given that he has no idea when it can happen within the NHS, he says simply 6 months plus, and slipping all the time.”
(Southampton – wait 0-2 months for cervical laminectomy).

“Wait is too long as I am in constant pain requiring a number of daily painkillers that have considerable side effects – i.e., nausea and giddiness. I cannot eat well and have poor sleep. I am so restricted and in pain. How can I be on an urgent surgery list?. I despair.” (Southampton – wait 7-12 months for spinal surgery).

“I am very upset because I am normally a fit and healthy active sports person who due to the delay has seen huge weight gain due to lack of mobility. The delay has also caused my treatment to be more evasive as the initial injury could have been dealt with by keyhole surgery, this is now going to need knee replacement instead. Mentally it has made me less confident, outgoing and have lost my self-esteem. The stress of all of this also caused me stress related psoriasis which I have just had to have 10 weeks of hospital treatment for as well. I can now not walk without use of a brace or crutches.... I have had to change my job to more of a work from home job.” (Southampton – wait over 2 yrs. for knee replacement).

“Totally acceptable. Can’t fault the care, expertise, compassion and urgency experienced by the medical professionals linked to Southampton General. Only issue I have is that the administration process appears to be dreadful! I was under the impression that following such major surgery I would have a follow up Consultation .. absolutely nothing other than with my GP 6 months on. Appear to have fallen out of the system!” (Southampton – waited 3-4 months for heart surgery).

“Ridiculous! Every time I am sent an appointment, I am then sent a letter cancelling and rescheduling my appointment for another 3/4 months’ time. This has happened at least 7 times now.” (Southampton – wait 1-2 yrs. for gastro treatment).

“Acceptable given NHS is over stretched. However, disappointed when I then got a phone call advising me of my appointment that it was a shared video link appointment along with 10 other patients. Then it was very stressful because I received no information on how to sign onto the video call or a phone number to contact anyone for any information. I called the hospital switchboard 3 times twice I got answer machines and no call back and the 3rd time, the day before the appointment, I eventually spoke to a lady who subsequently emailed the info. The whole experience was very unsatisfactory, given that I had expected to go to Princess Anne and personally meet with a Physiotherapist on a one-to-one basis.” (Southampton – wait 5-6 months for prolapsed bladder ongoing treatment).

“Angry, frustrated. My life is hold, my pain is bad and I'm at risk of losing my home because I can't work and because I can't work I'm at risk of losing my business.” (Southampton – wait 7-12 months for completion proctectomy).

“I was told at my 6-month review with my surgeon that it would be a minimum of a year before I would be able to have a procedure to match my breasts following my breast cancer. I have just completed a year of cancer treatment and had hoped to put everything behind me. Disappointed and left down, I also feel guilty for having these feelings because I know that this is not considered a priority, my cancer treatment was the priority, and this was dealt with promptly.” (Southampton – wait 7-12 months for breast surgery).

And some positive comments:

“Impressively all planned pre-assessment and pre-op activities have been conducted within reasonable time window. Outstanding IT connectivity between Departments has resulted in timely action for next phase of treatment.” (Hampshire – wait 1-2 months for prostate day surgery).

“It was great, my breast nurse suggested in my results appt that we preliminarily book my mastectomy and anc. in for about 2/3 weeks' time it

would never have been that quick without her suggesting that". (IOW – wait 1-2 months for cancer surgery).

"Pleasantly surprised. I had to have a steroid injection in order to diagnose precise problem. It showed I needed hip replacement. The effects of the injection lasted only 10 days, and I informed my surgeon, Mr xx, who immediately put me on his waiting list. There had to be a 3-month delay post steroid injection before I could have surgery, but I didn't have to wait more than a couple of weeks after that to have the surgery. Because I am considered low risk, it was carried out on the NHS at The Spire hospital. Couldn't have expected better. Very pleased indeed." (Southampton – waited 3-4 months for osteoarthritis surgery).

"I was hugely impressed and pleasantly surprised! Having been told I needed a cataract removal in my left eye, I was expecting a wait of at least 6 months and was amazed when I had the procedure about 3 weeks later." (Southampton – waited 0-2 months for cataract surgery).

When asked "Has the length of the wait had any effect on you, good or bad?" the following shows the percentage of those who stated the wait had a detrimental effect on their health and/or wellbeing.

	Percentage
Hampshire	51%
Southampton	56%
IOW	82%
Portsmouth	14

Some examples of feedback:

"I'm in pain every day. It impacts the quality of my life. I have been given compassionate and brilliant care from primary care (GP) to manage my condition and the consultant at the hospital have been wonderful, but it is hard to know the operation waiting for would make such a difference." (Hampshire – wait 7-12 months for endometriosis operation).

"Yes, we were so worried that we run out of money as my husband was not able to work and off sick. This stressed both of us and had a significant impact on our life". (Hampshire– wait 7-12 months for hip replacement).

"As with every medical situation the problem gets worse over time if not treated and your always encouraged to seek medical help early, this has been over a year since my first appointment, the problem is getting worse restricting me to be able to do normal everyday activities, like opening packets, tins, jars, luckily it's not my right hand otherwise I wouldn't be safe with a kettle. On bad days I cannot drive as I cannot take the handbrake off. So, the effects on my health and wellbeing are negative". (Hampshire – wait 7-12 months for carpal tunnel day surgery).

"Yes, I am in constant pain, and it has increased over the time of waiting. My lifestyle is limited, and I cannot travel. I am now having times of the day where I feel very sad and blue" (Hampshire – wait 7-12 months for bladder surgery).

"It affected my relationship with my husband, he is now very tired because of having to help me with everyday tasks and bear the brunt of housework and gardening. I wasn't able to drive which affected my social life and freedom and generally at times I thought life was not worth living." (Hampshire – wait over 2 yrs. for arthritis treatment).

"It would be nice to have an idea of when surgery might happen. Or even to be told it won't be for a given period so that I could get on with life in the meantime. At the moment I am reluctant to plan anything because I have no idea when an appointment might become available. I recognise this is difficult with the backlog after the pandemic and the need to deal with urgent cases as they arise." (Hampshire – wait 7-12 months for heart operation).

"Negative, not sure what I should be doing to help myself". (IOW – wait 1-2 yrs. for cardio follow up).

"Negative - my pain returned in under 2 months from my last full Hip Operation, and it is so severe that I am on the full dosage of pain capsules and liquid. The pain relief from the Morphine no longer lasts 12 hours, I have difficulty in getting up in morning and I can hardly walk (with sticks) Conditions deteriorate from when I get up to 2pm when I can barely move". (IOW – wait 1-2 yrs. for hip replacement).

"Negatively of course... I have very little quality of life and feel I am just destined to sit in limbo". (IOW – wait over 2 yrs. for knee replacement).

"Negatively. I am on 3 different pain medications, medication for anxiety, medication for depression. Pain relief has minimal effect. I have lost friends as I don't go out much. Lost confidence." (Portsmouth – wait 1-2 yrs. for arthritis surgery).

"I am very concerned regarding this problem, which is seriously affecting my state of mind, as this can be a FATAL CONDITION." (Southampton – wait 1-2 yrs. for liver varices treatment).

"Sometimes negatively. For example, for my ongoing eye treatment, I have had to attend eye casualty in between routine appointments a few times because of deterioration in my eye before my next appointment, which if I had not attended the eye casualty, would have led to serious damage to my eye and made the condition worse. I experienced considerable amount of pain and discomfort during this time and contemplated a lot about whether to visit the casualty or not." (Southampton – wait 7-12 months for eye treatment).

"I am my husband's prime carer, but as the waiting went on and the condition got worse, and I feared the arm would break catastrophically. I found myself in the situation of trying to fit into an emergency plan what should have been planned surgery with a specific date to work around. This was impossibly

difficult and extremely stressful.” (Southampton – wait 7-12 months for failed metalwork surgery on broken arm).

“Negativity. It’s a condition that affects me daily and has resulted in me taking a lot of time off of work also my fertility is affected by this so the longer I wait for the surgery the less likely I am to conceive naturally.” (Southampton – wait 7-12 months for endometriosis treatment).

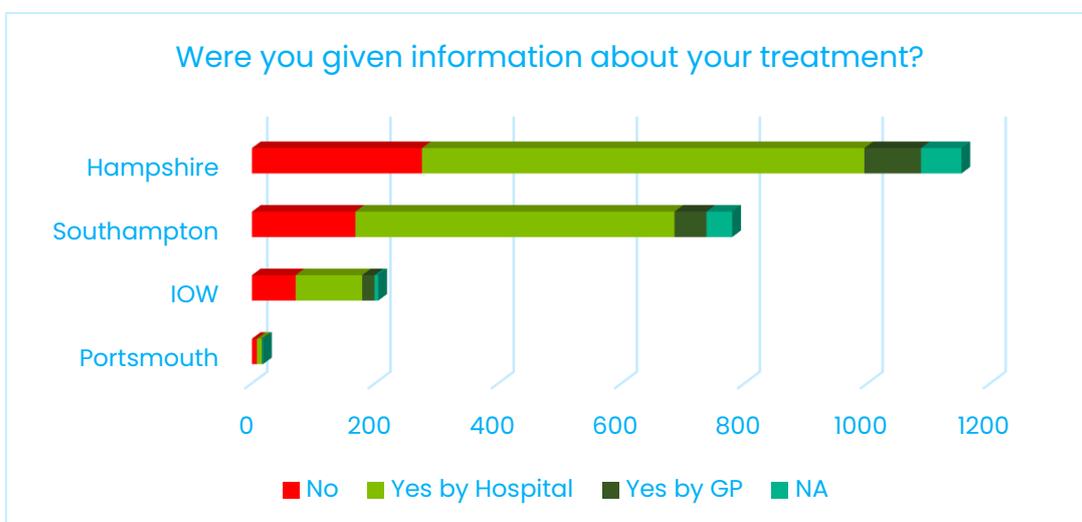
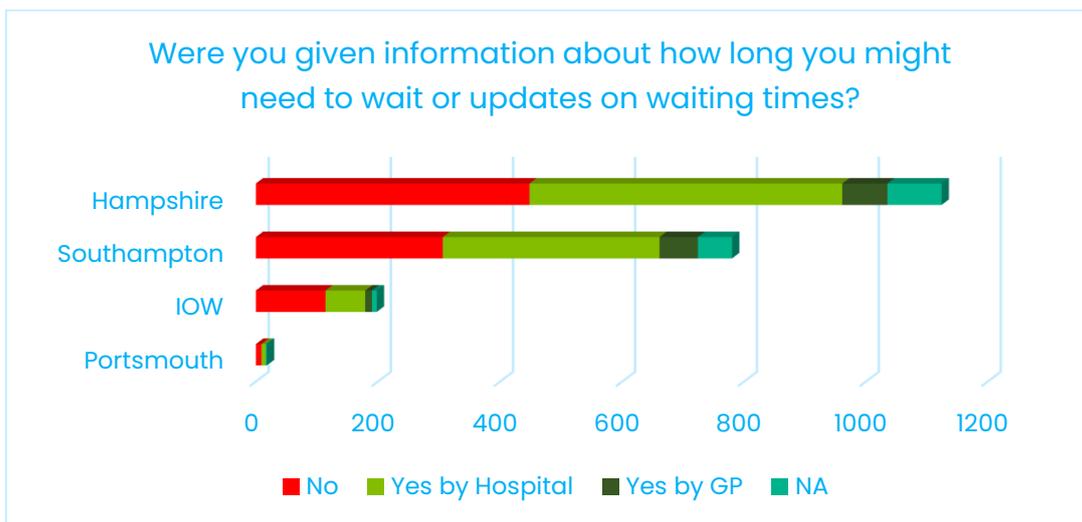
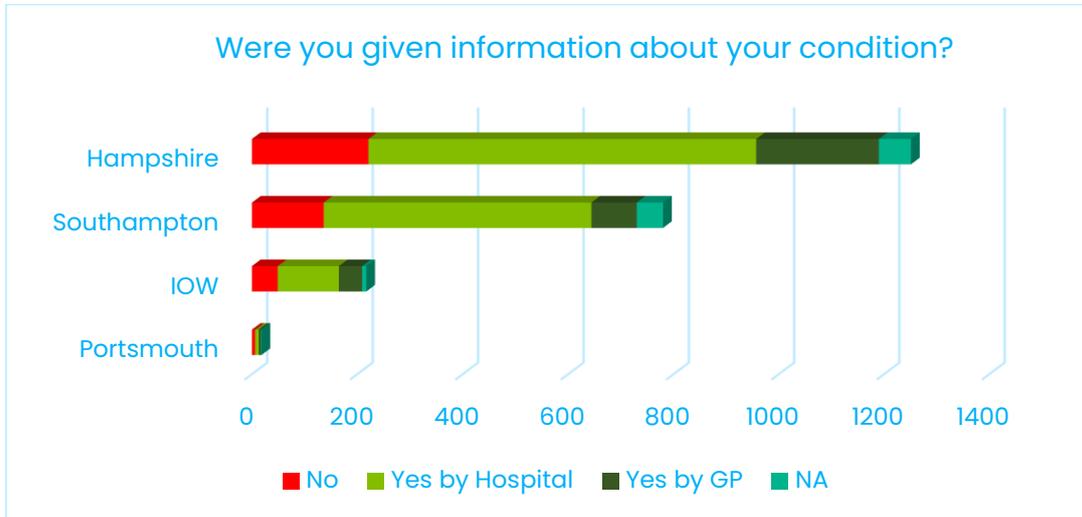
“It was just frustratingly slow and somewhat concerning after my initial referral was by my optician who cheerfully announced, “you might be going blind”. (Southampton – wait 7-12 months for glaucoma surgery).

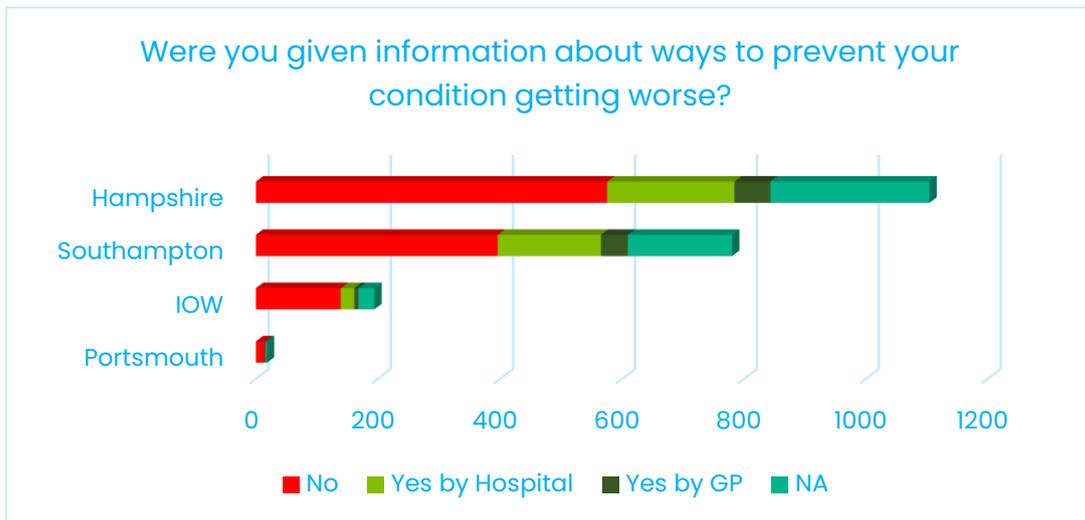
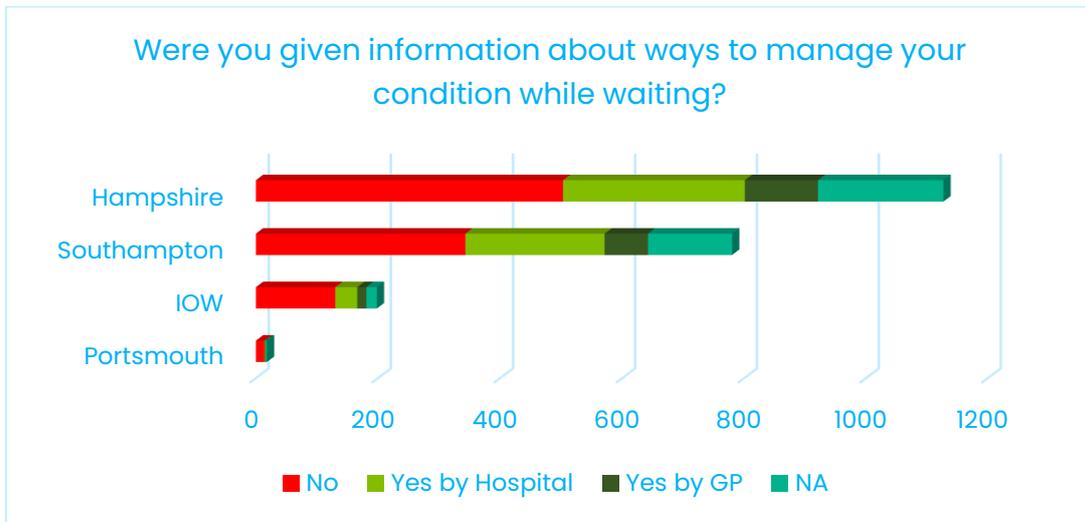
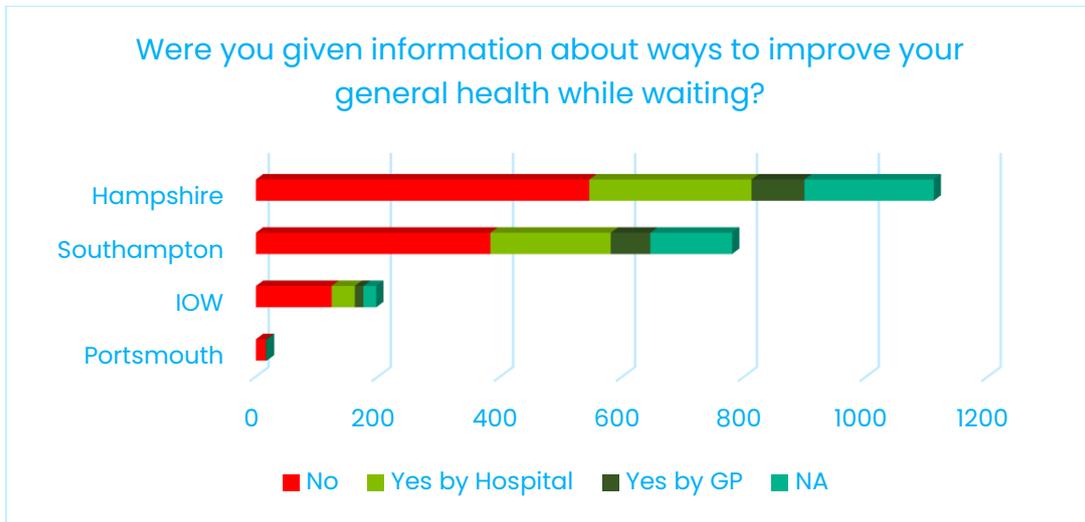
“I cannot eat solid food, nor can I sleep lying flat due to the compression to my windpipe. I was sat in the hospital on xx date for this surgery from 7:30am until they cancelled it at 3pm due to no beds for aftercare. This is completely soul destroying and a disgusting way to treat patients. This whole wait has affected my mental health badly and I now need antidepressants. Imagine how you would feel living in hell for 15 months unable to swallow properly or sleep properly. Not to mention the other side effects of the condition I deal with daily on top of the terrifying worry something more serious could happen should the swelling get worse!!” (Southampton – wait 1-2 yrs. for goitre surgery)

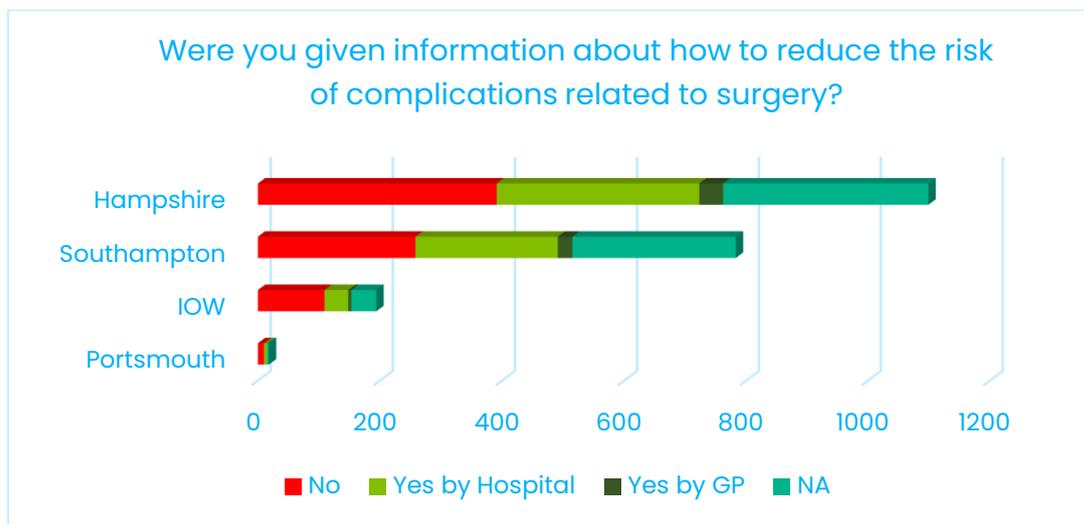
Healthcare Advice and Support While Waiting

(Results of those that responded to these questions)

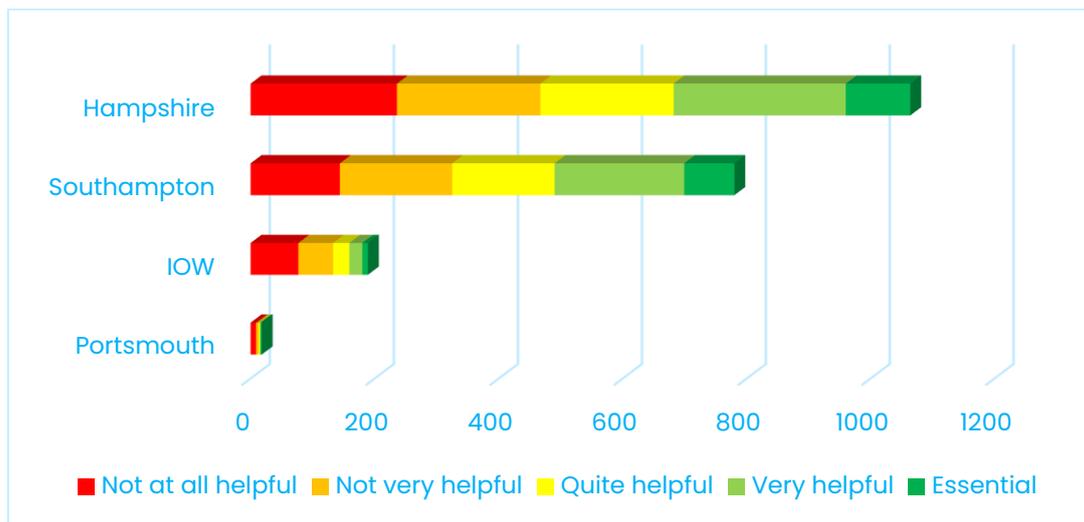
When asked if they had received information from the hospital or GP:







When asked “How helpful did you find the information/support you received?”:



Note: Given the wide range of conditions and wait times it’s impossible to know what information or support people should have been given.

Some feedback about information received/not received:

“Information received at Pre-Assessment was the most helpful.” (Hampshire – wait 7-12 months for hernia day surgery).

“The video and booklets I was given by Basingstoke hospital were very informative and I used them extensively both before and after the operations.” (Hampshire – wait over 2 yrs. for osteoarthritis operation).

"I did not receive anything. I was not told how long the wait would be, what to do whilst waiting! I have chased the secretary to be told I wouldn't hear for months, no idea what to do till then", (Hampshire – wait 5-6 months for ongoing shoulder treatment).

"I have had absolutely no communication from anyone since being referred for surgery over 6 months ago." (Hampshire – wait 5-6 months for general operation).

"Due to previous health issues, my husband has difficulty in understanding issues when these are given. there was nothing in easy read, or with pictures to explain the pain, and what they were planning to do." (Hampshire– wait 5-6 months for hernia operation).

"The Consultant was extremely helpful with respect to the treatment. He explained in detail and I found that very useful. However, he did not know how long I would have to wait". (IOW – wait 3-4 months for prostate operation).

"For eight months I was sent from one colorectal specialist to another until finally referred to orthopaedics in February 22. I am on the waiting list for surgery, but not provided with any detailed information as to how to deal with my condition in the meantime nor what the surgery will entail". (IOW – wait 7-12 months for spinal operation).

"I don't understand a lot of the information given or the terminology". (IOW – wait 7-12 months for cataract surgery).

"I didn't see the same DR. throughout the entire wait process. I seemed to be forgotten and only after several calls to the department did things start moving. No one really knew what was happening and no one communicated anything to me". (IOW – wait 1-2 yrs. for carpal tunnel surgery).

"I have no contact details for anyone at the hospital, the last outpatient appointment the doctor wasn't very helpful he just gave me more medication. My GP gave me a number for the hospital but it's just an answer phone and no one replies to your messages". (IOW – wait 1-2 yrs. for bladder surgery).

"Other than the referral letter I have had no contact from either go or hospital. I contacted the hospital 6 weeks ago for an update on an appointment and was told "it will be months." (Portsmouth – wait 7-12 months for vaginal prolapse operation).

"The information you mention above would be incredibly helpful to know. I haven't been told anything other than the appointment will happen and I'll get a letter about it, but 18 months later and I don't even have the letter, even after chasing it both by email and in person". (Southampton – wait 1-2 yrs. for cardio treatment).

"I don't think the GP has provided good information on how to prevent the condition from getting worse. I am relying on information on Google to know how best to manage it." (Southampton – wait 1-2 yrs. for hernia surgery).

"Apart from reading about my condition online, that is the only information I have gleaned, and I should have thought my GP, or the hospital would be better able to advise me, although I do realise that Covid has a lot to do with these things." (Southampton – wait over 2 yrs. for hernia surgery).

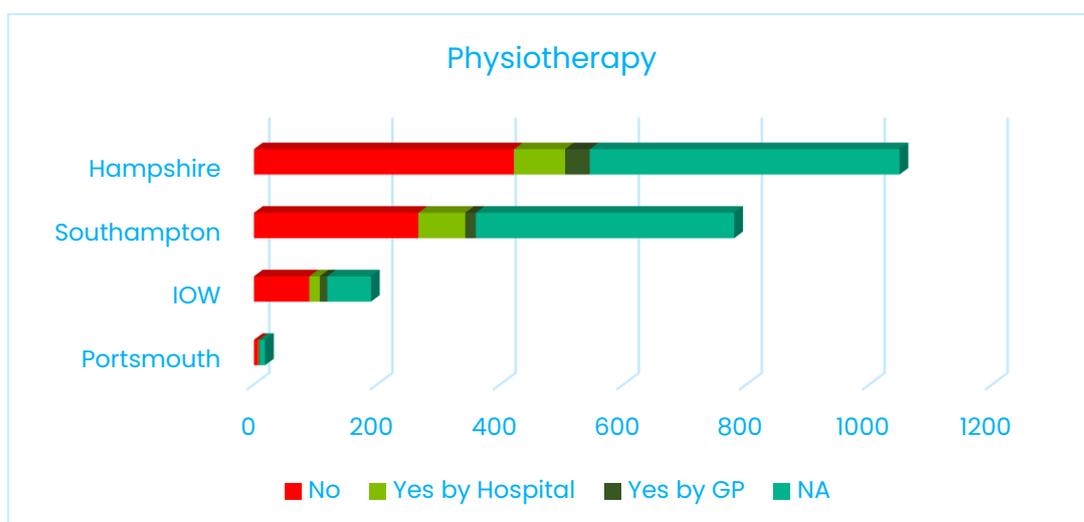
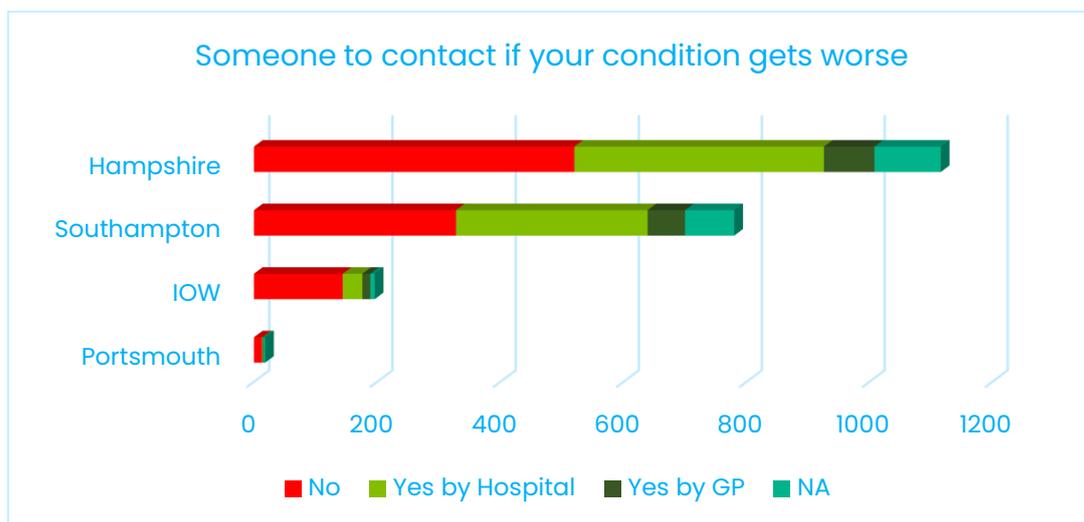
Some positive feedback:

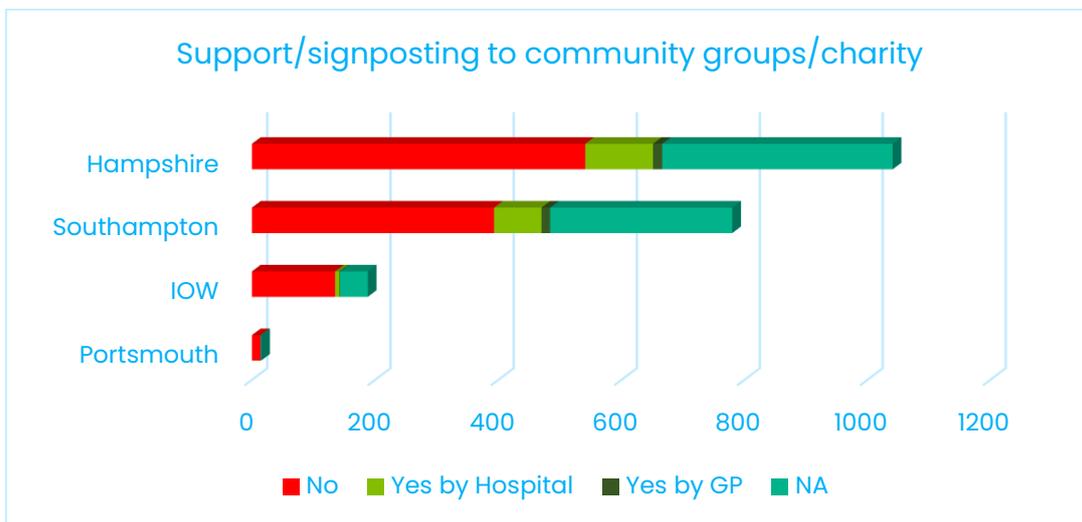
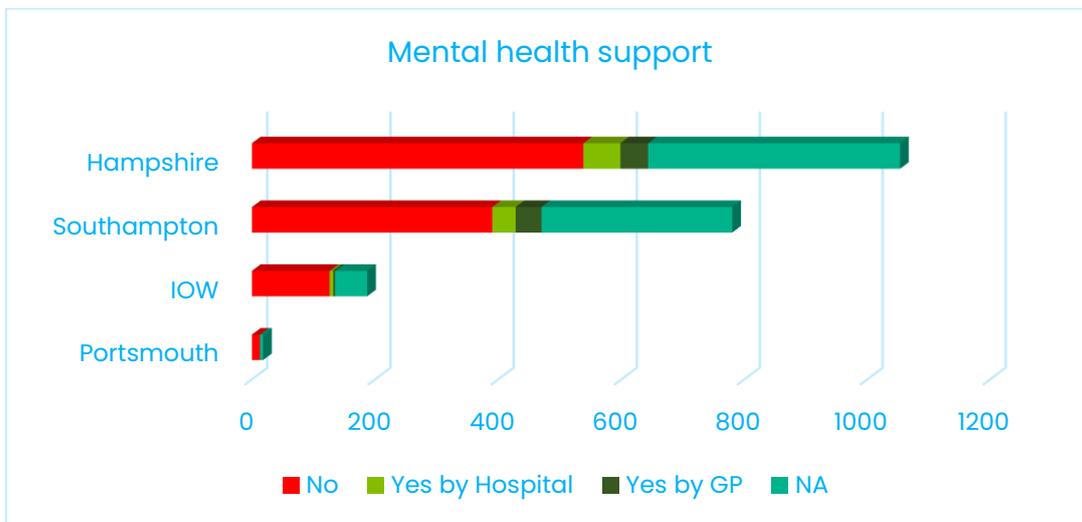
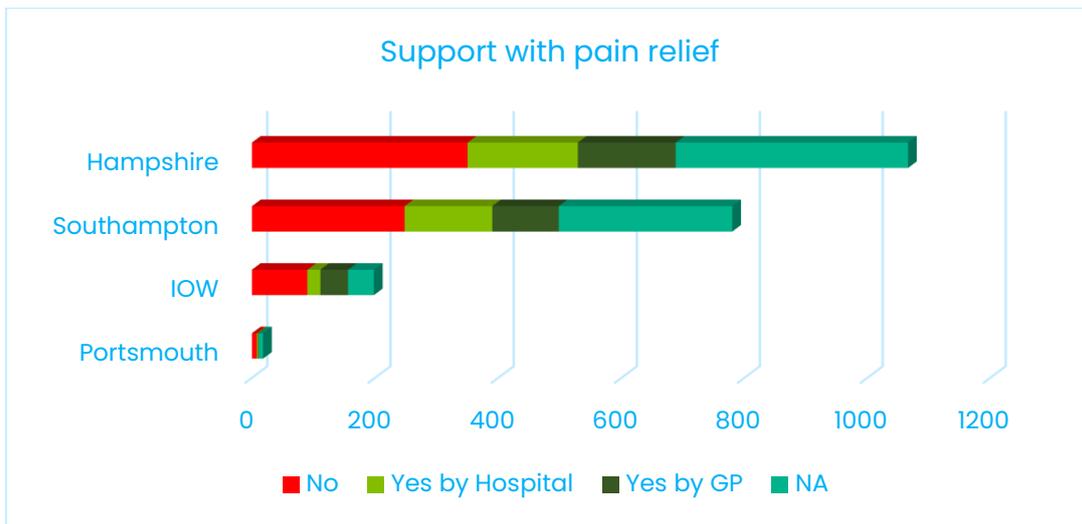
"In January I attended a half day course called surgery school and my husband as carer also attended. It explained risks and how to prepare for the operation to improve my chances of recovery" (Hampshire– wait 7-12 months for bladder operation).

“When I explained new issues, over the phone, to the Allergy consultant in January 2022 he listened and gave me advice and information that I needed to understand my current situation. He was kind and caring and explained things so that it was easy for me to understand, which I appreciated. He informed me what would happen next and what he was going to do to try to get my face-to-face appointment waiting down from 2-3 years to maybe 1-2 years.”
 (Southampton – wait 1-2 yrs. for allergy to antibiotics issues).

“I was given a lot of useful information which has helped me to understand my proposed operation.” (Southampton – wait 0-2 months for heart surgery).

When asked “have you been offered any of the following?”:





When asked “Being in good health when having treatment is believed to make a difference to how well the treatment goes. Were you given any advice or information to help with your health while waiting? For example, advice on smoking, weight, alcohol, exercise?”:

	Yes	No	NA
Hampshire	23%	47%	30%
Southampton	29%	41%	30%
IOW	27%	55%	18%
Portsmouth	3	14	1

When asked what information they were given:

The majority of advice given (across all 4 areas) related to weight management, reduction of smoking and alcohol intake, exercise and nutrition.

When asked “Is there any information or support you would have liked to receive while waiting?”:

The majority of respondents wanted:

- An update on their appointment/waiting time.
- More information about how to manage their condition/pain and aftercare.
- People also asked for information about stress, counselling and mental health support, home care, local support offers, nutrition and what to expect from hospital procedures/treatment.

When asked “Have you heard of or used “My Planned Care” (app, website or link from hospital?)”

	I have not heard of it	I have heard of it but not used it	I have used it
Hampshire	84%	6%	4%
Southampton	90%	6%	2%
IOW	71%	12%	6%
Portsmouth	16	0	2

Note – there was minimal difference from those still waiting and those who have already received treatment in terms of whether they had not heard of it, not used it or used it.

Feedback on use of Winchester for future treatment

(Results of those that responded to these questions)

When asked: “In the future, would you be willing to have any planned face to face pre-operative assessment at a hospital in Winchester prior to having your procedure at a hospital in central Hampshire, if that meant you could be treated sooner?”

Note – for the survey in IOW, this question was phrased as “.....prior to having your procedure at a hospital on the island.....?”

	No	Yes	Yes, but I would need some help from the NHS	Number of responses
Hampshire	25%	58%	7%	970
Southampton	37%	56%	7%	744
IOW	47%	36%	17%	180
Portsmouth	3	14	1	18

When asked “In the future, would you be willing to have planned day surgery at a hospital in Winchester if that meant you could be treated sooner?”

	No	Yes	Yes, but I would need some help from the NHS	Number of responses
Hampshire	23%	67%	10%	980
Southampton	33%	59%	8%	734
IOW	45%	42%	13%	173
Portsmouth	3	14	1	18

When asked “In the future, would you be willing to have a planned operation with overnight stay/s (inpatient) at a hospital in Winchester if that meant you could be treated sooner?”

	No	Yes	Yes, but I would need some help from the NHS	Number of responses
Hampshire	23%	68%	9%	992
Southampton	32%	61%	7%	736
IOW	41%	41%	18%	172
Portsmouth	3	15	0	18

When asked what help they would need from the NHS to attend a hospital in Winchester, most people answered help with transport or with transport costs. Many were concerned about public transport being available at the right times (especially relating to ferry times/cancellations etc from IOW) and whether parking would be available should they travel using own transport.

Respondents from the IOW expressed concern over the distance to travel and especially the cost of ferry and potential overnight stays in Winchester if appointment times do not enable them to return home same day. People expressed concern over what would happen if ferries are delayed or cancelled. The additional time needed to attend was also a concern (adding travel time to appointment time and availability/timing of ferry crossings). There was also concern over how family etc could visit (given the same issues).

Examples of comments received:

“Yes, provided I was seen by a suitably experienced and qualified Consultant Dermatologist at a suitable hospital in Winchester and that once referred I received continuity of care from the same consultant of suitable experience and qualification”. (Hampshire respondent).

“I can't drive and don't have someone to drive me and don't have the money to pay for a taxi. I live in Gosport. It's a long way to get to Winchester”. (Hampshire respondent).

“I live too far away, don't drive and public transport links are poor”. (Hampshire respondent).

“Post injection period is not conducive to a longer journey”. (Hampshire respondent).

“Although Winchester doesn't seem that far away, I feel I would need to be close to home in case there were some problems with my husband's care”. (Hampshire respondent).

"I am unable to predict my future needs, so therefore can't give a positive answer. For example, if it were another cataract operation I would wait and attend more locally as I now have a good eye but if it were something causing me extreme pain I would go where the treatment would be faster". (Hampshire respondent).

"I would be happy to have pre-op assessments in Winchester, but I would want my surgery to be at a hospital that the consultant that I am under - who has treated me many times before - works at." (Hampshire respondent).

"..... my life can get back to normality please, please allow me to go to Winchester County Hospital urgently as I cannot wait much longer in this state of mental and physical distress". (IOW respondent).

"I would be happy to have treatment in Winchester as long as appropriate support to get home afterwards and good liaison between mainland and NHS staff here on Island. I.e., If a short-term package of care needed then this needs to be in place and support to get home provided". (IOW respondent).

"I would be prepared to be treated in Winchester if it meant being treated earlier, even though it would make visiting near impossible. But I am concerned about how I would get there and more importantly get back to the island and home". (IOW respondent).

"Cost mainly but it's also a bit of a big ask for my carer to come over twice". (IOW respondent).

"If the appointment was in the morning I'd have to get a ferry the night before and stay over and that isn't affordable. Public transport from where I am to where I need to be doesn't exist. If I had a Winchester appointment and the ferry is delayed or cancelled, I would get accused of missing an appointment

and the stress of being accused when there's nothing you can do isn't bearable for me". (IOW respondent).

"Absolutely no, no no no no why should islanders travel to the mainland for treatment when not in good health – this is just another cutback to break the NHS – what's left of it!!!!!! IMPROVE NHS SERVICES AND TREATMENT ON THE ISLE OF WIGHT – WE ARE THE MOST SOUTHERN PART OF THE UK AND SHOULD NOT BE DISCRIMINATED AGAINST BECAUSE WE LIVE ON AN ISLAND". (IOW respondent).

"He would go anywhere within reason if it meant getting treatment sooner". (Portsmouth respondent).

"I need a carer with me at all times also appointments not 8am in morning as need travel time" (Southampton respondent).

"For some items/specialities, Winchester is not the same standard as Southampton and so information may not be the same quality. Really problematic to park in Winchester. For basic assessment, like vital signs, X ray etc, I fail to see why this cannot be organised at the South Hants or Spire or Nuffield according to the speciality. Afterall the same surgeons work at these hospitals! So orthopaedic at Nuffield and eyes, cardiac at Spire etc etc Seems obvious? is the problem availability of triage pre-op nurses, medics or anaesthetists of investigative facilities or theatre time?" (Southampton respondent).

"Because I want all my information to be in the same hospital so that when a consultant is looking at my care they have ALL the information to hand, not lost in another hospitals systems. I work in the NHS, it is far from 'joined up'." (Southampton respondent).

"The parking is dreadful in and around Winchester and costs way too much." (Southampton respondent).

“Difficultly getting to Winchester. I don’t have any relatives that could take me and it’s 2 bus journeys which would take at least 2 hours travelling.”
(Southampton respondent).

“The inconvenience of treatment delay is greater than the inconvenience of traveling to Winchester & back.” (Southampton respondent).



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Healthwatch Southampton,

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Healthwatch Portsmouth

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