

Appendix D: Patient Accounts

Herefordshire and Worcestershire COVID-19 Response

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Patient profiles

Name ¹	Description <i>(Includes: age, gender, living arrangements, working status, health issues)</i>	Healthcare services accessed during the Pandemic
<u>Alan (Pt 1)</u>	<ul style="list-style-type: none"> 72 years old – Male Living alone Retired Co-morbidities: Spinal stenosis, osteoarthritis, non-Hodgkin's lymphoma, type 2 diabetes, bipolar, lymphoedema and tissue viability issues. 	<ul style="list-style-type: none"> Podiatry Cancer services Mental health services GP Surgery District Nursing
<u>Jane (Pt 2)</u>	<ul style="list-style-type: none"> 79 years old – Female Lives with husband Retired Has Ulcerative Colitis 	<ul style="list-style-type: none"> GP surgery Pharmacy
<u>Helen (Pt 3)</u>	<ul style="list-style-type: none"> 52 years old – Female Lives with husband 52 years old and two children Works in teaching part time Inoperable neuroendocrine cancer: tumours on pancreas and in liver. 	<ul style="list-style-type: none"> Cancer services
<u>Jackie (Pt 4)</u>	<ul style="list-style-type: none"> 52 years old – Female Lives in a one bed flat with 22 year old son Gave up work due to ill health Terminal cancer of the liver and bowels Previous heart surgery and is hard of hearing. 	<ul style="list-style-type: none"> Cancer services
<u>John (Pt 5)</u>	<ul style="list-style-type: none"> 87 years old – Male Widow, lives alone, supported by son Frailty, glaucoma and tinnitus 	<ul style="list-style-type: none"> GP Surgery Pharmacy Eye specialist
<u>Michael (Pt 6)</u>	<ul style="list-style-type: none"> 70 years old – Male Lives alone Retired Has seizures, fainting and spinal problems 	<ul style="list-style-type: none"> GP surgery Hospital admission Neurology
<u>David (Pt 7)</u>	<ul style="list-style-type: none"> 84 years old – Male Lives alone 	<ul style="list-style-type: none"> GP surgery

¹ Names have been changed to protect patient identity.

	<ul style="list-style-type: none">• Blood clots on lungs, high blood pressure and back problems• Bereavement during COVID-19	<ul style="list-style-type: none">• Hospital admission
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Alan

I'm Alan...

I'm 72 years old. I used to work in specialist engineering and moved here for work in 1985. I don't have any family ties but I'm in a relationship with a female friend who lives down the road, we've been 'engaged' for 32 years and we do not co-habit. I can't get to her at the moment because I'm waiting on delivery of a mobility scooter and I have to use a car because I can't walk further than 20 yards without great pain. I'm not isolated in the community as I have my friends here.

I have six long term conditions. In 1974 I was diagnosed with schizophrenia, in 2012 the diagnosis was changed to bipolar and mania. I also have non-Hodgkin's lymphoma and had chemotherapy and immunotherapy for this in 2017. I also have Type II Diabetes. My spinal stenosis is in the lumbar and cervical region in the neck. The osteoarthritis, in the lumbar back region and knees, causes problems severe restriction in my mobility. I've also got lymphoedema, where fluid collects on parts of the body, and tissue viability issues. I've got discharge from lymphatic wounds in the legs and the bandaging for those prohibits being able to put shoes on at the moment.

The only restriction on my lifestyle has been in the last three years because of my arthritic knees and also pressure points on the feet that have caused physical mobility issues and pain. At the moment I am finding it more difficult with mobility problems to use the stairs because of arthritic knees and my spinal stenosis pain in the thighs.

My life during the pandemic

During the lockdown I did follow most of the announcements on the television. Now it's becoming piecemeal, it's all over the place, and really, I pity anybody who is worried and dependent upon what they hear as to what they can do, because the information's all over the place. People maybe shielding and maybe not going to the shops, or they might be working under the old guidance. The cancer specialist says I'm shielded, and the GP says I'm not shielded and the letter from the cancer specialist nurse says I'm vulnerable but I'm not extra vulnerable!!

I did have the facility, via a next door neighbour, to have shopping got from Sainsbury's home delivery. I got on a preferential system, whether that was because of me or because of her family arrangements at home I don't know. The shopping was able to be delivered to her front door, so they didn't come on to my property nor me into theirs. It was all done at the front door. I've been going to Tesco's just to do shopping myself, just to give a chance to be away. And in fact because of my appearance with my infirmities, with my mobility and also the bandaging on my legs, I was actually given preferential place in the queue by people who probably took sympathy on me.

Normally my social activity would be with my friend down the round however, after the twelve weeks, I went in my car. An old work colleague who would come to see me once every two or three weeks by train hasn't come because of the train situation where only essential journeys are

allowed. Perhaps in the future, with certain changes in regulations, he would possibly visit from a social aspect.

I think I went out during VE Day, I ventured down the front road with my camera, no more than about four or five houses down, to take pictures of the union jacks and various ceremonial things that were put in windows for VE Day celebrations. But that was the only time I ventured out of the property, maybe for twelve weeks.

I've got face masks now and get texts to wear it for visits to the GP, but just sourcing face masks for those shielding/ housebound could be difficult. If you're in the NHS it's your internal supply, but the man in the street could have problems in sourcing his PPE equipment.

I can't get anywhere else now because of dressing on the foot, as I was saying, it's the shoe wearing, so I'm housebound again, but I've got friends, I've got the neighbour next door to run me down to the doctors and we both wear face masks. I'm not depressed about having to do what I do. I've donated some cheques for the NHS since back in May.

My recent experiences of health and care services

Normally I would be seen by a consultant in the cancer unit at the local hospital, but I was advised by two letters that the consultations would be by phone and the blood samples that were needed before the cancer consultation were taken by the district nurses because I was housebound.

I've been seeing a podiatrist at the local podiatry clinic since last December for assessing my feet for diabetes and a pressure point on the bottom of my right foot. At my last visit they were lining me up with insoles for the slippers but visits to the clinic have stopped during the pandemic. They were doing three weekly check ins on the phone regarding the state of my feet where I assessed my own feet, for sores bleeding and the pressure points. The phone consultations have all been OK.

I've had to come away from home visits for the district nurses, I now go to the surgery, for my diabetes, but obviously with wearing a face mask and not going inside until appointment time and not waiting in the waiting area too long so as not to cause crowding or cause cross infection. The GP surgery were trying to limit the amount of patient activity at the surgery. My surgery, that's in Kidderminster, were doing phone assessment with the patient, but for anybody who had got a smart phone, they were doing video link as well. I haven't got a smart phone, so I think it was useful that I had face-to-face instead.

I recently had a blood test done at the practice, and also the doppler effect for diabetes, but that was done as an add on to me attending there to get the lymphoedema discharge dressed. So they were killing two birds, or three birds with one stone. I think the surgery had pretty well shut down from what I gather.

For my bipolar, I had a letter from the local specialist unit to say clinic visits won't take place during COVID. I haven't rearranged because it's going to be a telephone appointment, but I imagine it's ok because my condition is not serious at all. Maybe a specialist will be able to assess me and my responsiveness over the phone.

My lymphoedema has seen a build-up of fluid in the lower legs, large blisters form full of lymph fluid and these eventually burst. Since about April this has occurred, and they have fortunately been treated by the district nurses. Over the past week and a half I've got to go down to the surgery where I saw the specialist nurses because of the more serious nature.

I got Care and Support 24 because of my spinal stenosis and my limited ability to move the body around. They do domestic cleaning. I had to pay, it's not cheap. The reason I mention this is the NHS is of course about keeping their properties and surfaces clean but not our homes.

I've got an appointment next week with the high street dentist which I pay for with a regular monthly payment, called Den-Plan, because I've got a problem with painful gums. I had most of my teeth, all of my teeth removed, so I've just got dentures. They're working double shifts to cover the backlog situation.

How I feel about what's changed

Home phone calls are not a problem for me because I'm OK. I'll say it's been effective for me both with the bipolar and also with the cancer. But one thing I would say is that during this COVID period for mental health with telephone consultations the use of speech and the reception of the words being said in the ill person's mind would have an effect upon their faculties or abilities. A change there could cause a major problem for anybody with a mental illness.

For example you've got somebody who's got a knife in the street and there would be somebody walking past them, he hears 'shall we go in that shop now', the use of the word 'now' might be enough in his mind to trigger him to stab somebody. The fact is in society words that are heard are so relevant. Somebody who's having a phone consultation for a mental illness problem, could be in dire straits, the confusion, the doctor might say certain words to them that will cause them to walk out under a bus. They might be better with face-to-face.

I'd be wary of that mental health one, anybody may be taking things the wrong way, and of course the paranoia type of situation can affect people, people who have been furloughed and so on, who might worry or have anxiety causing depression. I'm sitting pretty because it all happened to me in the past and therefore, I'm protected now, but the great shame for a lot of society and I wish you all well, is all I can say.

Jane

I'm Jane...

I'm 79 and it's just me and my husband in the house. I've got two daughters and four grandchildren. I've got ulcerative colitis, which is an ongoing thing, there's no cure for it. I've always had the worry that I would have a perforated bowel. It's always at the back of my mind, bowel problems, that possibility.

I've been very lucky throughout my life; I've really led a healthy life. Since 2015 when this ulcerative colitis came up, I've had about five or six colonoscopies and I've been hospitalised a couple of times when it's flared up. Unfortunately, a lot of the medication that they've given me hasn't suited me. I have gone on the internet and looked it up and I've also joined the Crohn's Society. We look after ourselves very carefully and we eat very sensibly. I saw a dietician (privately) for my ulcerative colitis, I paid out and had about four consultations to find what things didn't suit me and I shouldn't take and advice about what I should eat.

I lead a fairly active life. We go out quite a bit and I'm an NHS trained volunteer, so I help at the Mother & Baby clinic usually, but not through lockdown. I'm part of a forum for older people, about 45 older people, we meet usually once a month and I do all sorts of things, I do bits of sewing, I knit, I like gardening, I like listening to music and I'm just very active. I've always been fit and doing exercises and things. I did aerobics for years and we've been doing exercises and going walking since the pandemic every day, so that's me in a nutshell.

My life during the pandemic

I suppose it was quite a shock really. A very dear friend of ours died suddenly of cancer and it was only diagnosed when he was at Stage 4, so he only had a short time to live and he died, towards the end of February, and we'd actually gone to his funeral on the 18th March and then the lockdown came. I suppose numb is the best way to describe it, it was such a shock and he was such a lovely chap and he'd never been ill; we'd known him for 16 years. My next thought was *"oh gosh, I'm never going to be able to accept being tied to the house all the time"*. I hate being tied to the house; I'm never going to cope with this.

We have gone out for a walk every day all the way round the park and back up. I've done the family shopping because my husband who's 83, has health problems. He's had prostate cancer and he's had three heart attacks, so he doesn't come into the shops. He drives me there and then he waits in the car and I go and do the shopping. So we've coped and it's been better than I thought.

I'm fine. I just get on and do things. I don't let things bother me. I don't sit and mope, I just have a very positive outlook on life. My husband's trying to have a positive outlook although he can't walk too far, he gets out of breath, but he's been doing the walks with me. There's no way even now I would go to a restaurant. I wouldn't take the risk. But we've met up with my daughters and

they've come here, and we've met up with a couple of the men and their wives from the prostate group that my husband has a friendship group with. We've just socially distanced in the garden or our large conservatory.

We haven't seen one daughter much because she lives further out and it's been difficult for her during the pandemic, but my other daughter and her husband, we have seen, but we've been very careful with our social distancing. Government guidance has been a bit confusing. We haven't listened to all the things on the TV. We've watched a couple and I haven't got the patience to listen to all that. We have a newspaper every day, so we've caught up with that and the things on the television and the news.

My recent experiences of health and care services

I had problems just before and at the very beginning of the pandemic I had a flare-up and I was passing blood. I'd got through to the GP surgery and asked for a telephone consultation and after I was triaged by someone it took a while, but I had a telephone consultation and all they could offer in this situation, was an eight week course of steroids. Well steroids to me are a bit like a sticky plaster. I had a temperature of 38°C so I was prescribed antibiotics. Another doctor at the surgery said *"unfortunately really you would be better off with a colonoscopy but we can't do it because they're not doing them at the moment"* so again I was put on steroids. In the last couple of years not long after I finish a course of steroids, my symptoms come back, and I start getting blood in my faeces. So I was worried about that happening again.

I did get a telephone call from one of the doctors in the gastro-enterology department at Worcester. I was told that if I did have any problems again with my ulcerative colitis, I was to ring the doctor's secretary and I got a letter with a telephone number and contact for the doctor's secretary.

I'm very concerned about the way the phone message works when you call the doctor's surgery. I emailed my surgery, which they haven't responded to yet. There is a standard thing that all surgeries are using that the NHS have probably told them to use and it takes about four minutes of listening to the various things and also they tell you it might be useful to have a pen and paper ready – well if you haven't got one when you've sat down to the phone, that's a problem – but then also it goes on and it's not until towards the very end when you get the choices of the possibility of getting a telephone consultation with your GP.

From my experience with the forum, I feel that that's discriminating against elderly people because not everybody has patience or understanding to listen to all those messages. You have to go through it to actually talk to somebody and we feel quite strongly in our group about age discrimination. Old folks haven't all got smart phones or are internet savvy, so therefore all these

things which are going on, they're not considering the fact that a lot of older people don't have those things to hand.

I made an appointment to have a blood test at the surgery, when I got there I had to wait outside, in the hot sun and then somebody came so I gave my details and they went off. Then they came back and asked me again all sorts of questions, my date of birth and so on, and then said to me *"you haven't got an appointment"*. I was so cross. The only response I got was from the receptionist said, *"I'm awfully sorry, it's my fault that your appointment was cancelled."* Fair enough its human error we all make mistakes and I was happy the apology. Went I went another time it was raining outside so I waited in the car until they came to get me.

Due to the pandemic I put my prescription request in the letterbox outside the GP surgery and then they electronically send it to the chemist and then I phone and check to see if they've got it ready and then go and fetch it. But they did deliver it a couple of times because I was over 70. But the lady that was a volunteer doing that, had to go back to work, so it wouldn't be delivered anymore. It's fair enough, I'm quite capable to go and get it.

How I feel about what's changed

We had a letter about the lockdown, but I don't know whether it was the government, because technically because we were over 70, we were supposed to be in absolute lockdown. I don't agree at all with what they're saying about it being less likely to have face to face consultations with your GP in the future. I think that's a very wrong, face to face is needed to be able to talk to you and get some idea of what needs doing. I was just happy how it was before even if you had to wait two or three weeks sometimes to get to see a doctor.

My medication hasn't changed. I'm still on the same medication. The only problem I have with that is apparently one of the things that they could affect is hair loss. And my hair has been falling out, for a couple of years now. My appointment with the consultant which was due at the end of June was cancelled and I've had a letter now to say that my next appointment is not until next February. I can't see me going until next February without having a problem so it will be interesting to see.

Helen

I'm Helen...

I'm 52, I live with my husband and two sons (17 years old and 19 years old). I'm a part-time teaching assistant. I reduced my hours because of the cancer, I was just so tired. I've had NET (Neuroendocrine) Cancer for over 5 years now.

I have a tumour attached to my pancreas, which is inoperable, it's wrapped around an artery, somewhere where they can't get it off. And I've got a Jackson Pollocks liver, so I've got lots of little splats and tumours on my liver. My liver still functions, and I seem to be able to have a glass of wine! I have monthly injection treatments, check-ups every three months with the oncologist and twice yearly scans.

My life during the pandemic

As soon as the lockdown was announced, my head teacher said to me on the 18th March, *"we prefer it if you weren't here because we're worried about the risk of any infection to you."* I really miss my job. Watching the briefings and news on television, I didn't want to risk anything myself so realised it's for the best, so that's been a big change.

I had my monthly injection within a week after lockdown. I was able to go up to the hospital to have it done, but things were different I had my temperature tested as I went in and there were a lot less people about. Then I got the letter to say to shield myself from the 26th March, so from then I was shielding.

It's very strange because after you've had cancer for over 5 years, you're dealing with all of that, and finding it's OK, but then there's something that could get you that isn't what you're actually looking after yourself for. I wasn't as nervous in the very initial stages, I became a little bit more nervous about myself when the rates were going up.

When I had my birthday, I saw so many people that came and sat on the driveway just to say hello, and I got messages from school, with we're missing you and stuff, which was really nice. I've missed just being able to go to work, and the interaction with children. I love that. Even on days when I feel really rubbish, working with little ones does really help. I kind of got my head back down with fundraising for NET Cancer UK and start making some more things to sell, making zebras, crochet things, and felt crafts and decorations and stuff. So I've got myself into that bubble and I've enjoyed gardening and going outside, that has been nice.

My recent experiences of health and care services

Previously I chose to have my injection administered at the hospital, because my children were younger when I was diagnosed, and I didn't want to keep the cancer in the house, as the injections need to be stored in the fridge and you receive a three months' supply. I was happy going every

28 days, getting my treatment done, coming back, dealing with any side effects, and then just get on with my life as if it's not really there. So that was one of the changes I had to take.

I've got a very good relationship with my Clinical Nurse, because we run a support group together for the NET cancer patients who've this cancer in the local area. We're so used to seeing each other once a month for my treatment, and she's still checking in with me once a month regardless, because now I'm self-administering my injection. They're in the beer fridge in the shed, that was my compromise to myself! I didn't want them in my house and my sons opening the fridge and seeing the massive boxes in there!

At the start of the lockdown, my CNS [Clinical Nurse Specialist] and I had a conversation about what might be best, and I didn't want to be going up to the hospital especially if it's putting pressure on anything, so we agreed then that I would have them administered here, so Healthcare at Home were booked. Under my CNS nurse's supervision, I administered the first one, then the lady from Healthcare at Home came to the house to do it. She came twice and I administered it while she watched. I do them myself now. I felt a little bit safer that way. She was following all the rules and masking up and everything, but she's travelling all around the West Midlands to different places and people's houses, and I'm having to sit here and wait anxiously for her to get through traffic.

Now I'll do it at 2 o'clock on a Thursday, it's quite painful in your leg, and I numb my leg for an hour, and do the injection myself. I am going to continue doing it myself. I made the decision that to do it on Thursdays and have a day off on the Friday to recover. I did have a little blip this month, because I didn't want to do it purely because of the size of the needle, it's a very surreal experience! But actually overall it feels OK, I have taken a bit of control back in the fact that I've been able to say well, I am going to do this here and now, and it's just me, I don't have to rely on anybody else. I might train my husband, but that might be too much of a temptation, it's like having a dart!

I normally have my scans in June and December. I had a telephone consultation with my oncologist, and he booked it in for June, I didn't have any delays on anything, efficient as normal. I had to go and get my bloods done at the hospital first, for my kidney function and stuff, which was fine. Didn't like the mask because it the first time I put my mask on. I've never seen it so quiet. When I went for my scan my husband wasn't allowed in. One poignant thing was when I had to stand to one side, while they wheeled down someone who'd been on a COVID ward, who'd obviously come off the ventilation, so the staff were all clapping and that brought that home to me, how it really is real then.

We have patient support meetings (funded by Neuroendocrine Cancer UK) which we've done via Zoom. You're seeing other patients who were going through similar things, everybody seems to be fairly positive. I'm having another oncology call, have one every three months a catch up check up

call, so that's been booked to talk about the next treatment and blood tests, urine tests and scan results.

I have had a Zoom consultation with my CNS, we speak once a month at the moment, because I've been helping her with these different types of video conferences locally, so I've been a bit of a guinea pig, to see how they're working. I think they're really good, quite relaxing because you can do it from home and allocate time to it, and it's nice to actually be able to see somebody's face as well. I'd be more than happy to keep doing that in future, if that's the way forward. You don't have to go through the stress of travelling, trying to find a parking space at the hospital, and waiting in the oncology room. If your appointment is delayed, it's usually because somebody else is having a pretty crappy time in there.

Even if I'm having a day when I've got one of my headaches, I could actually still manage a telephone call, but I couldn't necessarily manage a drive up to hospital, and a wait. I know that some of the older ones in our group that are a little bit more reluctant, who still like the idea of they're going to see the doctor. A call feels more centred to you as an individual patient. I don't know why, but it does. I think it should continue. I think it can free up a lot more time. As I've been a patient for five years, I've got quite a good relationship with my doctor. I probably wouldn't mind keeping in touch with him over the phone. If my scan results show that the disease was progressing, I think I could probably handle the information that way, but I think I would like to go in more face to face for discussing the next steps.

How I feel about what's changed

I'm quite happy to carry on with wearing a mask when I go anywhere, and washing my hands, and adhering to distancing and all of that. I go for walks and stuff and luckily have a garden. My only frustration is the people that aren't doing it. My worry is if I go back to school in September, within a couple of months I'll be off again, because of the fact that people haven't, that's my concern. I know I will be off because I will want to protect myself. The advice I've had was general. 1st of August you're not having to shield, and you can go back to work, just be careful, nothing specific.

I am a very positive and upbeat person, however I did have very dark low moments in it, everybody that had something wrong with them is probably feeling the same, lack of control. That was the biggest thing in that sense, it did affect me. Ultimately, I suppose it was taking control in yourself, and thinking no I am going to look after myself, and I am important, as opposed to thinking well I can go do whatever I like, it might not get me. That was a hard, I did have a couple of weeks stomping around, banging things.

All I can say is I cannot fault anybody, it's been smooth. I've not really experienced any difference apart from my injection. I was nervous at first about whether or not I would get my scan, because I

can't do a whole year not knowing whether or not the tumours have changed. I almost live my life by six months for that, and then by 28 days for the injection. So it's been managed very well.

Jackie

I'm Jackie...

I'm 52 years old, I live in a one bedroom flat with my 22 year old son, that was at university but has come home because of my illness and his own. I gave up work two years ago because I was too ill to work, but I didn't know what was wrong with me. Me being ill has affected my son, we're hoping to rehouse my son so that he can be settled for when my time comes.

18 months ago I was diagnosed with a neuroendocrine cancer of the liver and the bowel with an unknown primary. In October I had open heart surgery to replace two heart valves, because the carcinoid has destroyed the heart valves. I'm now in the process of having radiotherapy through a drip which is done over ten months, it started in July. My general health is deteriorating but OK.

My life during the pandemic

I first heard about COVID on the news on telly, didn't think too much of it to start with when it weren't affecting us, but as it started to affect us it felt a bit surreal, like it can't be happening, especially with an illness like I've got. I've limited time anyway. It's prevented me from doing a few things that I wanted to. Learning to live with it like most people, struggling about not being able to go out and do the things.

I keep up to date on Facebook or news. I don't put the telly on too much because it's like being bombarded. At one point it was 24 hours a day. It's hard to process when you have an illness anyway. I have nurses come in every day, so they tell me if anything's changed, rather than having the telly on.

We're having to live in a close confined space, my son's on the bed settee in the living room waiting to be rehomed, so we really struggled. Learning to live with one another under in a small space had put pressure on us, but we got through it. He's suffering with anxiety and depression and having to cope with the nurses coming in every day, so if he wanted to go out, he couldn't. We had to find things to take his mind off of it. It was hard to start with, but we've got into the swing of things a bit now.

At first, it's so scary, you don't want to go out or do nothing, you just want to stay safe in your own little bubble. As things have lifted a little, we have ventured out a little, because there's things we needed to do and sort out. It's been frustrating because we haven't been able to sort out anywhere for him to live and time's limited, I want to see him settled. I've got all these open boxes half filled with things that I'm going to get done and it's just put a hold on everything.

My son struggles with wearing his mask because he's anxious, so he gets all hot and bothered, so just going shopping is a trauma at the moment. We've tried having it delivered and, but it didn't work for us because I like to go and pick what I'm going to have, and they substitute things and you end up spending a lot more than what I can actually afford to spend on my shopping doing it

that way. I'm not going to be able to do that forever. While I can I want to do it. I haven't had the care packages or anything because I didn't need them, I've got plenty of friends to go and do the shopping. If I couldn't do the shopping, they did it for me. I've tried to stay as independent as I can. Sometimes you want somebody reassuring you that you're doing the right thing don't you? I don't like the isolation, I like to be able to go out and do what I want to do. I'm on a two week lockdown now before I go out for my treatment, and I'm itching to go out or for a drive or just bump into somebody and have a conversation with them. I like to keep busy. I don't like the fact that we had to do lockdown, but I understand why we had to do it. We're well informed about what's going on, but some of the rules have been a bit unclear like should we wear a mask or not.

We haven't ventured out very far yet because of me having treatment that's ongoing until January, so I've put a hold on things. It has stopped us from booking holidays or going away till February at least, if it's safe to do that you know.

My recent experiences of health and care services

Before the pandemic I was going to the hospital twice a week to once a fortnight for an injection, and I'd also got a syringe driver fitted where the community nurses come in and they filled it with medication every day for that. That's continued through COVID, they've had to be extra cautious. I was also having face to face consultations with different people because of the open heart surgery, I've got four specialists I was seeing, all face-to-face to start with but now it's all telephone and video conferences.

The video conferences are OK because it's hard when you're going to hear bad news, and you're at the hospital, and you've got to get back in your car and you've got to drive home afterwards, and your head's all over the place. Whereas on a video conference I was given quite a lot of bad news, I was told that if I didn't have this treatment I weren't going to survive till Christmas. I knew I'd go for the treatment, but I was a bit reluctant because of the side effects. But when they told me that, on the video call, I had my friend with me because I'm hard of hearing I sometimes miss things, it was more reassuring, the fact that I hadn't got to get in the car and drive home, and I could just deal with what they'd said not having to think about anything else. I'm glad I had somebody with me, I try to make a point of having somebody with me when I have a video call.

Injections have changed now because instead of me traveling to the hospital to have it done there's a specialist nurse that comes out. She only does these kind of injections.

The nurses coming in every day, have had extra precautions, extra PPE and they can't hang about, they can't talk to you too much. They take any bloods I've got to have done, then they have to travel and take them to the hospital straight away. They're new faces coming in, so it's took a lot of getting used to. I've struggled with people wearing masks because I can't see their mouth moving, and being hard of hearing, that's been a struggle.

I liked the fact that the nurses are coming in extra protected because you don't know where they've been before; you know you're clean and tidy. So it's reassuring that they take all their PPE off and throw it away before they go to the next one. That's a big thing.

Yesterday was the first time I contacted the GP because normally I go through the hospital and ring the specialist nurse, to be honest, I quite prefer to speak to a doctor rather than waste their time to go in with trivial things. I'll speak to them and then they decide whether they need to see us or not, which is what's happened this week, I've felt better about that really, because I felt I wasn't wasting anybody's time. It's just we had to wait nearly two and a half weeks for one specific doctor to ring us back that I wanted, so there is a bit of a backlog, because they're catching up with everything. But I'm patient, I can wait. It would've been good to have a phone call to check on you instead of you having to ring them. You do get that feeling that out of sight, out of mind but I've been in regular contact with people, especially now I'm having my treatment, they do keep ringing, making sure I'm at home.

There were no delays in my treatment I was probably one of the first patients to have treatment and it wasn't fully open the first time I went. It was strange going to the hospital as in I couldn't take anybody with me. You really need reassurance, you want somebody, if you haven't heard properly or if you've took something in a different context. They have got the specialist nurse there with me, every time I see a consultant, so if I haven't got it right, I can ring up the next day and say, *"Was that right what I heard like?"* and check with her. I'd be lost without the specialist nurses. They have been amazing.

Entering the hospital has changed, you get stopped every hundred yards and asked where you're going, that is reassuring that they're checking. Because I'm a high risk patient, I still don't go to the hospital unless I've absolutely got to. They bring the medication out to me and put it in the car, so I haven't got to go in personally, or somebody I know that works at the hospital will pick my medication up for me and bring it home. The precautions of wiping everything down, cleaning everything are all reassuring. I feel comfortable with that because they're trying to keep you safe.

The radiotherapy treatment I'm having at the moment has a lot of scans, and it's just really made it more aware of what's going on. I have to be enclosed into a room on my own, partly because I'm radioactive, partly because of COVID. That can be a bit isolating at times. It has been a life changing experience but at the same time I'm going through a life changing experience anyway, so it's doubly hard. It's bought home, you can cope on your own. It's just not very nice sometimes.

The changes are isolating, very isolating. I'm lucky that if I've got a really big problem, I can just pick the phone up and speak to somebody. Nine times out of ten if they don't answer then they'll ring me back, which is an absolute godsend. Now you're aware that you're breaking into their time, because they are really busy at the moment you know. You don't want to keep interrupting them or ringing them, so you wait and wait and wait until you think you really have to.

Yesterday was the first time he (my son) went to see a doctor face-to-face, about counselling. He's classed as a priority now so hopefully he can get to do that face-to-face, because he wouldn't talk to anybody on the phone. That's major step forward for us. At the doctor's he was like pacing the floor, he was sweating buckets and everything, so he's in a pretty bad way at the moment. COVID hasn't helped, because it's just encouraged him to stay in; he won't do anything unless he's actually got to. It's really impacted him. I've been able to get in contact with the housing, there's a lot of people needing rehousing, so it's set us back. It really has impacted us.²

How I feel about what's changed

I think they've [healthcare services] gone above and beyond with everything at the moment you know. They're doing everything they can for me. My only concern is my son, getting him settled before things get too bad that I can't do that for him. I think people with mental problems have struggled a lot, like my son.

I'm quite self-sufficient to be honest, but I'll reluctantly ask for help. When you've got a terminal illness you want to make the most of the time that you've got left, visit people and go places. That was hard to process because you just think every day is wasted. Hopefully we're back on an even keel a little, and I am allowed to go and see people after, 20 days after my treatment. I can go back to having visitors for an hour and things like that.

² Since Jackie's interview, they have received the news that he can be successfully rehoused

John

I'm John...

I was sat here thinking about writing a book on me life, there's me forces life, my own private life and the RAF. I'm 87 and I live in my own at home alone. I retired at 65, when the wife contracted cancer. So that upset the apple cart completely.

All my right side is injured, I've cut myself in half. In 1955 I come off a motorbike and broke me leg. Then in 1985 I had a car accident and broke the same leg. Since the care accident I've suffered from panic attacks. Then around 1998, I broke me leg at work, the same one. That was three times, so I've got restricted movement of legs and a brachial plexus injury in my arm, where the nerves in the shoulder stop working, so I've got no upper muscle in me arm. My hearing's gone now, I can't hear different tones, I've got tinnitus. It's just like running water all the time, I get like reverberation, this developed when I had me car accident. I've had to live with it. I had this glaucoma and they took the cataracts off and laser treatment on one eyeball 2/3 years ago.

When the wife died, I had to have a bit of bereavement help. I had a young lady come out to the house to help me through the black parts of it. I managed to pull meself together and keep going. I lived as normal, the way I used to do it. I'm happy enough, but I've lost all me confidence, which has made life real hard.

My life during the pandemic

I was confused. I didn't know what was happening. I didn't understand it. I had a bereavement, when the pandemic started and that's what knocked the confidence out of me completely, she was a very good friend who I'd known for about 70 years. She knew the wife as well. I wasn't allowed to go to the funeral. They were only allowed five. So sod it, I can't go anyway because I've got no transport because the buses and the taxis weren't running at the start. So I was totally isolated.

The brick wall wasn't necessarily me all the time. If I decided to do something, the government would say "*no you can't, that's banned*" and I was running into this brick wall all the time, no matter what I wanted to do. If I wanted to get on the bus I couldn't because you weren't allowed to, they just made life hard.

I was always master of my own way, I'd do my own shopping and everything. My son was always there, he's just down about three miles down the road, but what I said to him, "*I'll lead my life, you lead yours*", this is what we agreed on. I've always been accused of thinking of other people rather than meself. I don't want to make a fool of meself. I have got a mobile phone which me son just bought me this year, but I haven't learnt it. I can use it if I want to call him, but eyes can't focus.

Me son had seven days furlough at the start of the pandemic at the same time and this is where it goes all confusing for me. I didn't see government advice but watched it on telly, I done it on my

own free will, with me son. He'd do me shopping if I wanted anything and he'd take me shopping. It's very hazy, how I went about it.

I don't really understand how I am coping with it. I've more or less shut off. I got stuck in the house and I thought that's it and I couldn't get out because I wouldn't drive because of the glaucoma. I don't push myself enough. I want me hair cut but I'm frightened to walk up to the barbers in case I fall over, because I'm on me own.

I'm terribly confused. I've got to ask my son because as he says, *"you're old enough to look after yourself!"* I agree with what he's doing, he's making me do it. He works and isn't here, so can't just nip out and take me.

My recent experiences of health and care services

Few months before the pandemic I had the glaucoma in me eyes done at the hospital. I couldn't get there or anywhere because of not being able to drive. I was using the ambulance service, the hospital service, they were marvellous; you couldn't wish for better people. That's the only way I could travel.

I was due for another visit still under the eye specialist when this pandemic started to see how the treatment was going but they cancelled, and I haven't been able to get in since. They didn't contact me, I contacted them and learnt that everything was cancelled so I jumped on the ambulance service and tell them because they need notice. Its upset me. They sent me another appointment, but I couldn't get any transport because the ambulance service wasn't running, and taxis wouldn't take you. Nobody would take you. Even your friends wouldn't take you to the hospital and my son had just come out of furlough.

It's a job to get hold of my GP because he won't come to you. They put you onto 111. And talk it through that way. So again I think to meself well, *"I'm fit, I'm all right, why the devil should I bother?"* So I just grin and bear it. That's how I feel. I'm a bit belligerent in a way.

I've never called him [GP] other than, he was supposed to ring me back about me blood pressure and it was just the nurse that rung me and told me. It's a job to pinpoint him. They pass you round the buck without talking to the doctor himself. It's confusing. You can't get past the receptionist. They diverge you off into another category, another channel, to help you.

Last week I had my six monthly review on tablets, it was requested on the bottom of my prescription that I picked up from the chemist 'time for review'. The GP took the blood pressure and blood tests that he wanted. Me blood condition is A-OK. There was nothing wrong with that, but me blood pressure was sky high. I had to go back again a fortnight (last week). The blood pressure was right back down. She said, *"your health is for OK for your age"*. So I was pleased in

that respect. If I don't feel very well, if I think I'm going to pass out, I usually think to meself, "*well you are a doddering old devil, you've had the all clear, what are you messing about at?*"

How I feel about what's changed

I'm frightened of a heart attack, to be honest, that's why I try to keep meself as calm as I can. So I've got these niggly thoughts in the back of my mind. I've got me brown paper bag to breathe in with a panic attack.

I still can't get to grips with reality, "*Why is it happening? What have we done to deserve it?*" It's mentality I suppose in the old mind. Why is it when I decide to do something, something at the end has stopped me? At least I've got somebody to call on during the day. I've got me son at night, he's just down the road, I can ring him if I want to, but I won't ring him because he's got his work to do, he's got his life to live.

From yesterday, my neighbour has been on a fortnight's holiday and his daughter said, "*I'm coming over for a cup of tea*" and I said "*OK*". I was too frightened whether I would pass anything off her. So I went over to her garden and had a cup of tea. You know what, that made me feel marvellous. That was wonderful to me, it was only a half hour, but it made it a lot more relaxing. I always go for a walk every night. And people now, just to say "*hello, how are you, good afternoon*". If only this bloody virus would go.

Michael

I'm Michael...

I'm 70. I am retired now. I live by myself and have done for years. I served in the military for six years, 251 days. Then I worked in Littlewoods for a while, then Westminster City Council until it went private. My health started to deteriorate about 1979, I had rheumatoid arthritis. I couldn't walk properly. When you're road sweeping you've got to be very careful, especially in London. I was having loads of tablets and they fired me because I was having to have time off on medical grounds.

I keep fainting, a lot of seizures and black outs. It's been happening for a few years now. It's a lack of oxygen and I can't breathe properly, they've got worse. I broke my right hip twice. I fractured it the first time then I fell down the steps and I broke it, so I got a new hip replacement. I've got spinal problems, because of the black outs. About two years ago I fell over again, backwards and I fractured my spine in three places. They know what the problem is with my spine, but they were trying to find a solution, but they won't touch me until this foot is healed. I had what they call two nails on one toe. They did a minor operation on it, they burnt it out. It never really healed properly and as time went on, it got infections and went septic several times.

My life during the pandemic

It came as a shock, because we were all living a normal life and all of a sudden, this pandemic comes. Your life changes. You've got to be careful. In the lockdown a lot of people still went out. It's a bit of a nightmare really because one minute they're saying one thing, we all have to wear masks, and *"oh we'll start letting people in"* on the news and then they stop it and say *"no"*. It's a confusing time at the moment you just don't know what's going to happen. Only been reading about it in the paper, because I like to know what's going on. My sister don't talk about it and neighbours don't want to know.

It's a shame. The government knew it was coming, what did they do? Very little to start with. When it hit us it was panic stations? They put out all the rules and regulations and explained everything in more detail and what not. It's a shame. You've got to wear masks now wherever you go. You see people in cars wearing masks and a lot of people are walking around the street, they don't wear them. So I've done that, when I go out on the mobility scooter to my local Tesco's I wear my mask. I usually go at 6am in the morning when they open, get what I need, and come back on the scooter and I stay in, I don't go out again, unless I have to go out, which is fairly rare.

It's a confusing time. I try to carry on as normal, you know. You've got to carry on. I just do it on my own. I'm not too far from the shops, so I'm happy with that. Now I've got a couple of people coming in, if I need anything else, they go and get it for me.

My recent experiences of health and care services

I go to the clinic here now but if I've ever had to go to the hospital, I'd get a taxi there and a taxi back. But when I had to go see a specialist I asked for transport. I was informed through the hospital what to do on the letter on who to phone to book the transport. That worked for me.

About a month ago the district nurses were coming out twice a week, they sent me to my local GP and he referred me to hospital. Three days later the ambulance picked me up. It was like a mini ambulance type thing come from the village. When they took me, I had a funny coloured toe, it started to go black and my foot swell up. They amputated it under local anaesthetic. They'd done the operation and the very next day said, 'you can go home now'. So I booked the transport and it brought me home.

When I was discharged, I was given the wrong drugs, they were for a cancer patient. Age UK helped sort it out with the GP. They put me on an antibiotic course in case there was any infection, and painkillers. The district nurses still come out, but only once a week on a Monday, before, it was twice a week they were coming to change the dressing (on my toe). Its healing, I can put my foot flat now.

Since being home I've had mini seizures, when I've been on my own. I've got a thing called Tele Care, it's an alarm system, you carry with you. When you feel it coming on you can hit the panic button and the ambulance will come and take you to hospital. The paramedics will come out first. When I've fallen. When I come to, then I'll press it. I find it a bit difficult getting off the floor. They said it's a lack of oxygen. The lad that comes around, he found me one time. He hit the three 9s straight away. My oxygen levels have dropped to a serious level. They put me on some blood tests and put me on oxygen, and a couple of drips as well; one was a vitamin drip and one was a water solution drip.

I've got an oxygen mask, I came home with one. I've got no oxygen though. So if it reoccurs again, I might have to hit the panic button. They said I was going to have oxygen. I haven't received any yet. I got in touch with my doctor, and explained the situation, and he said "*oh, I'll refer it back to hospital*". He said they're still on a reply. I'm still waiting. I don't know what's happening from a week ago. I've never had oxygen just had the mask. I'll have to ring the hospital to find out what's happening, I've got a phone number on the appointment card.

For my spine I'm under a different hospital they would have rung me to get it done and come and get me. I told them what happened, and they rang my GP and then said, "*we'll wait until your foot has healed*". So they wouldn't take me in. My foot is fully healed, but I've still got a bit of a scab on it, which they won't take off, for fear of infection. I can actually stand with my foot flat on the floor and walk with it now. I'll contact the hospital.

When you call the GPs, the answer machine comes on and the only way you go to the surgery is through an appointment over the phone. Recently it's been difficult to get through to the GP, having to wait a long time, being cut off and the system was completely down for a few days too.

Everything is just taking a bit longer now. Beforehand, you know, you had a panic button and they were there within minutes because we've got an ambulance station down the road, but now you've got to wait. You don't wait too long. If it's an ambulance they send the paramedic out first. He will assess the situation and if an ambulance is required, they'll come and take you to hospital. If it's serious then they get an ambulance there straight away. They've always got a couple of ambulances parked out in our hospital, minor injury unit because they operate there as well.

How I feel about what's changed

There's not so many ambulances around anymore. When we had that lockdown the ambulance service was cut down in size and the government says you've got to do this, you've got to do it. They've cut down everything. It's a big change in our lifestyle, it's upset the system, I think.

Since the pandemic episode started, when you go to the GP or hospital now, all the nurses and doctors wear masks, and all the patients have to wear masks. It's a big change, you know, from being normal before all this happened. Everywhere you go in the hospital, you've all got to wear a mask. It would be nice to get back to a sort of normal life. We've got to be very, very careful. We've still got to do the two metre or the one metre, whichever it is. I do what I'm told to do

I just want to get the spinal cord thing sorted and find out what's wrong because they won't tell you over the phone. They know what the problem is – I think if I've damaged me back, it could be something to do with the nervous system. I still fall down but now the legs won't fall underneath me. Me arms and hands, I get a numbness in me fingers when it plays up. Once my GP can refer me back to the hospital, I can talk to them.

I think the [health care] services could have been done a little bit better, you know. A little bit more effort put into it. But we have to live with what's happening, so there's not a lot we can do about it unfortunately. I'll carry on as long as I can. It would be nice to get back to normal life again, as they say. If this pandemic comes back again, it will come back even worse. We've got to be ready for it.

David

I'm David...

I'm 84 and live by myself. I've always had back problems for the last 20 years and got to the stage where I had to go into hospital at one time and had an operation on my spine, but my health is quite normal. I've had high blood pressure, but they reckon that's down to other things that were happening, so nothing serious.

My wife passed away recently, at the beginning of April. Then I got ill myself. I suddenly felt pains in my chest, down the side of my chest, next thing I know I'm in hospital! My wife was in care home for about fourteen months, before that she was in hospital for quite a while. It was a hell of a journey getting to the first care home she was in. Whilst my wife was in care home, I went up every day. The first one was quite a way, it took an hour to get there. Then we managed to get her moved down the road from here, which takes five minutes to get there. That was a relief really.

My life during the pandemic

On the television we heard things about it in China when it first started and I thought oh here we go again, another flu outbreak coming out of China. I think this is the third one isn't it? I heard how bad it was getting over there and I never imagined it would get this far, never. I always thought it would blow over in no time, but it keeps rearing its ugly little head.

I've got no feelings about it at all. I get it, I get it, I mean, there's nothing I can do about it, I mean, it's the kids I worry about more than anything. I was a bit down with my wife being in a care home, otherwise I saw my kids, well my one daughter and my granddaughters quite frequently. My eldest daughter I didn't see so much because she's got cancer and been advised to keep away from her. I do worry a lot about that, that really does concern me.

I've found no problem with [guidance], I thought that it was quite clear, simple enough. My daughter had already been told when I came out of hospital, I had to self-isolate for a month. In lockdown I couldn't go out, I used to go out quite regularly in the car, just for shopping or go down the town or around on my scooter. My friend who used to come round every week, and he had a very serious illness he couldn't do anything because of lockdown too. My daughter set up the iPad for me to watch films, but I am terrible with computers, can't get my fingers round the keyboard! I was going to have computer classes but with COVID it's not on.

It's strange really, it's a strange feeling, I mean, I was on my own anyway, with COVID it got worse because you see your neighbours, but they had to move away from you. I'm lucky, I've got brilliant neighbours, like the one side, I've only got to knock on the wall or go outside and shout over the fence. They both got my number, if anything happens and they don't see me at all for anything, they got the key number so they can let their selves round. They're very good. I'm blessed that way.

My recent experiences of health and care services

I've never had any problems. Whenever I've had anything wrong with me, I've always been able to get treatment. My doctors are brilliant. Since my wife got dementia, somebody would ring me and ask if everything was alright, even now since she's passed away. At the early stages we had some care support from the NHS it was only half an hour a day. Then the social told me *"you wouldn't be able to manage it at home"*. So I blame myself for that. I had a hard time, I felt really guilty about her going into a care home.

Both my son-in-law's, my grandson-in-law and I, all drive. So there was always somebody on hand to help me with transport at any time. My neighbours would help too. I had to see my doctor once, that was a strange feeling, they had masks on obviously and gloves and they just examined me and that was the only difference. The rest of the time it was about my wife, I get upset at times, I do miss her. Even though I saw her every day sometimes I might just as well have not been there. She couldn't remember who I was, but she missed me. And I can't describe it, it was a very strange feeling. I wouldn't wish that sort of thing on anybody. It's a horrible, horrible thing to happen.

I never really had anything go wrong with myself while she was in the care home till the very end. I had two clots on my lungs. I woke up in the middle night, with terrible pains down my side, I couldn't breathe properly, every time I took a breath, god the pain was terrible. I was worried about COVID, but I phoned 111, I was worried about phoning them, I thought am I phoning them just for indigestion or something like that, but they acted very quickly. While I was talking to them the ambulance arrived outside. Next thing I know I'm in the ambulance and they wouldn't let me take anything, they had to get me in straightaway- the only trouble I had was getting in touch with my family because I couldn't remember any of the telephone numbers! They sorted me out pretty quickly, I mean, it only took two and a half/three days and I was on a drip thing first for clearing that up, then they gave me another run through the 'doughnut' scanner.

They wouldn't let me out until COVID started they said, *"we don't want you here but with this COVID thing we don't want patients coming in with you as weak as you are"*, because I'd lost a little bit of immune system, and they just didn't want me there. They sent me home with the blood thinners with the understanding that if anything did happen with pain again, I was to give them a ring, they gave me a number to ring. It worked out alright, they were good as gold in the hospital, can't fault them. I've had a couple telephone consultations asked a few questions about my health and how I was feeling, if I was getting any more pains. They were very clear and precise.

The only time I went in was afterwards to have my tests done after the pains in my chest to see if the clots had cleared up. They treated me as best they could, I had to take blood thinners. And I had that one time when I knocked that mole on the back of my back, it started bleeding and I couldn't stop it, it just bled and bled! I phoned the hospital, 111 and they said you better get up the hospital and they phoned the Casualty and when I got there, I explained to them what was

going on and the tablets I was taking, and they see me more or less straightaway. They were clearing the wards out and deep cleaning the wards, each ward.

They cauterized it to stop the bleeding and they told me to take the dressing off within a couple of hours of getting home just to make sure and my neighbour came round and she's a nurse, she had a look and she put the dressing back on and said "*leave it the rest of the night and then see how it is in the morning*". I'm supposed to be having it removed. I phoned the doctor and they're going to get me in as soon as they possibly can, which is going to be a bit more difficult again because it looks as though it's going to start rearing its little head again. We looked up about my lung problem with my daughter, she was worried more than me, she didn't want to lose me as well so close to her mum.

I've always found the health service to be very good, I can remember the times when there was no health service, so I can remember how bad it was. Only thing that could have been better was when I was being discharged, getting my papers through, it took a long time to get them! That's normal because they have to make sure they're giving you the right medication, they check, they double check. I was waiting around for about six hours to get discharged. I suppose they were more concerned with patients who'd got COVID I should imagine. It took four hours last time, that was a minor thing. They were bombing, they were rushed off their feet. I've never seen a hospital so busy when they were getting ready for this COVID. Well there was actually COVID patients coming in, you could see them, and they were dressed differently to when they came in to see me.

How I feel about what's changed

I get a call from [Age UK] about every Monday evening and have a chat; long chat and it goes on longer than we thought sometimes! You get talking and before you know what's happening half an hour's gone by and we're only supposed to talk for about 20 minutes. We have a good old natter! My one neighbour's had me round a couple of times, "*come round and have something to eat*", you know, do a BBQ outside where we could sit apart from each other, you know. People are more considerate now, if you go to the shops, I just use my walking stick if I'm doing a light shop and people will say 'oh I'll reach that for you' people have been more helpful now.

Some people have had it worse, I'm at the age now where things are going to start to fall apart, I suppose! I'm alright, I'm fine, when I'm talking about certain things it upsets me a little bit. There's people I used to see, friends, we were very close. And since this pandemic, we don't see anything of them now. We talk on the phone, but it isn't the same.

Everything's been fine really apart from feeling a bit, lonely is the wrong word, I'm not lonely because I can always phone up somebody, just missing my wife every now and then I'll find something that triggers a little spell in me, which the doctor said will go eventually, because I'm

gradually getting rid of everything now. I've got no real concerns, I'm a little bit concerned about these blood clots if they come back again, but I know what to do if anything like that happens.

I can't honestly say the pandemic worried me at all, I was more worried about my family. I can't get my head round my daughter really. My main worry is my daughter, I still can't go round to see her because I've got a cold. I saw my great granddaughter for the first time in three months, week before last. Her granddad, my son-in-law, he spoils her, and I spoil her.

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