



Public Services Committee

Corrected oral evidence: Homecare medicines services

Wednesday 14 June 2023

3.25 pm

Watch the meeting

Members present: Baroness Morris of Yardley (The Chair); Lord Bach; Baroness Bertin; Lord Blencathra; Lord Carter of Coles; Lord Laming; Lord Porter of Spalding; Lord Prentis of Leeds; Lord Shipley; Baroness Stedman-Scott; Lord Willis of Knaresborough.

Evidence Session No. 1

Heard in Public

Questions 1 - 15

Witnesses

[I](#): Sarah Campbell, Chief Executive, British Society for Rheumatology; Dr Christian Selinger, Consultant Gastroenterologist and Chair, Inflammatory Bowel Disease Section, British Society for Gastroenterology; Ruth Wakeman, Director of Services, Advocacy and Evidence, Crohn's and Colitis UK.

Examination of witnesses

Sarah Campbell, Dr Christian Selinger and Ruth Wakeman.

Q1 The Chair: Welcome, everyone, to our first session of the committee's inquiry into homecare medicines services. We are delighted that the three of you have come along today to start us off. We are very much looking forward to hearing what you have to say.

I will let you introduce yourselves; that is always better. Without taking ages—it takes away from our question time—it would be really useful to have your name, the organisation you represent and your interest in this field.

You know that this is recorded, but, just to let you know, you will get the transcript and will be able to correct it before it goes into the public domain.

Ruth Wakeman: Good afternoon, everyone. I am the director of services, advocacy and evidence at Crohn's and Colitis UK, which is the patient charity for people with Crohn's, colitis and inflammatory bowel disease.

Dr Christian Selinger: Good afternoon. I am a consultant gastroenterologist from Leeds. I represent the inflammatory bowel disease section of the British Society of Gastroenterology—the clinicians looking after patients with inflammatory bowel disease.

Sarah Campbell: I am the chief executive of the British Society for Rheumatology, the leading membership society for rheumatology and MSK professionals across the UK.

Q2 The Chair: We have to declare our interests for this particular inquiry. I declare that I chair APS Support UK, which is a small medical charity. First, could you outline what homecare medicines services are? Who uses them? How do they work or how are they meant to work?

Sarah Campbell: A homecare medicines service can be described as a service that delivers ongoing medicines supplies and any associated care direct to patients in their own home with their consent. It is intended to improve patient care and choice of clinical treatment and meet government aspirations for care to be provided as close to home as possible.

Homecare services are provided to over 500,000 patients in the UK, at a cost of £2.1 billion. The sector has grown by 150% since 2011 and continues to develop and expand to meet both patient demand and the policy drivers to bring care close to home. The services are commissioned and funded either directly through pharma companies in about 80% of cases, or through the NHS in the remaining 20%.

In rheumatology, patients are usually what is described as low-tech users of homecare delivery services. Those are cases of uncomplicated administration of medicines that can be stored at room temperature or in

a domestic fridge. However, other groups of patients on more complicated therapies may also be in receipt of homecare and the service may provide special equipment, patient training and/or clinical support to administer the drug in the patient's own home.

Our members at BSR, in their clinical role, will normally assess whether a patient is appropriate to refer to a homecare medicines service. They will talk to the patient about the homecare delivery service, offer them further information, if necessary, and of course ask for their consent.

The clinician will then register the patient and issue the prescription paper to go in the postal service, and then the homecare medicines service will arrange a time to deliver the medicines and arrange any necessary nursing support or training that is required for that medicine. Over time, prescriptions are then re-issued.

The Chair: Could you say that bit again about the prescription in the post?

Sarah Campbell: It is a paper and postal-based system.

Dr Christian Selinger: The three patient groups we represent—rheumatology, gastroenterology and dermatology—are closely related. These patients have chronic inflammatory diseases that you cannot cure. These medicines are vital for controlling their symptoms, stopping them from progressing and keeping the patients well so they can be in their home and do not need hospital admission and so on. Any interruption or late initiation usually leads to the symptoms flaring up and being not well controlled.

This is the mainstay of advanced medicines for inflammatory bowel disease now. The vast majority of the medicines we have are now delivered via homecare because they are largely self-administered at home by injection.

We have certainly moved away from 20 years ago, when patients had infusions in hospital day units, and towards self-administered therapy at home. In theory, it is a wonderful model for the patient because they do not have to spend as much time on it and they are much more independent. It also saves the environment because there is no travel and all that involved. When it works it works really well, but the patient relies on that system delivering.

Ruth Wakeman: Homecare is really important for people with Crohn's and colitis. For people who are not familiar with the conditions, these are lifelong conditions. There is no cure, as Dr Selinger has said. Many people are diagnosed before the age of 30, so they will be at crucial points of their lives. They will be in education, school or university, building their career or having a family.

The conditions have really serious symptoms: painful, frequent and bloody diarrhoea; pain; fatigue; and a whole range of other symptoms as

well. People with Crohn's and colitis need to have their symptoms controlled so they can get on with their lives.

When homecare works well, it is fantastic for patients. People with Crohn's and colitis would far rather have their treatment at home. They do not want to take time off school or work to travel to hospital, with all the costs and time that involves. When it works well, it is fantastic for patients. It gives patients choice about having their treatments at home rather than in hospital.

The Chair: Can I ask a question on something I am not clear about? The patients in your groups would see a consultant; they would be under a consultant's guidance at the hospital. Is the prescription always dispensed by the hospital, or does it move to the GP to dispense it once it has been agreed what care the patient should have?

Dr Christian Selinger: These medicines stay under hospital prescription. They are usually issued by the consultant or the consultant's team. They are vetted by the hospital's pharmacy and then passed on to the homecare provider's pharmacy for processing there, and then they go on to delivery thereafter.

The Chair: The GP is out of this.

Dr Christian Selinger: The GP is completely out of this part of medicines delivery.

The Chair: That is, other than it being on the records as something they can see.

Dr Christian Selinger: Yes.

Q3 **Lord Blencathra:** I have no financial interests to declare, but I have half a dozen deeply personal ones. I called for this inquiry since I am a dissatisfied customer of a major homecare supplier. I believe the problem is widespread. I am a customer of three homecare suppliers supplying three different medications, mainly for my MS.

I complained very strongly about one supplier and its failure to deliver on time. I wrote to the then Secretary of State for Health, calling for him to remove all contracts from that provider. In that letter, I was also critical of the role of the Care Quality Commission. Finally, on behalf of the British Society for Rheumatology, I laid a Written Parliamentary Question in the Lords asking who in Government had responsibility for enforcing performance with suppliers. I am not an impartial observer in this and I have to put that on the record.

What are your assessments of how services are performing? Briefly, I have three different providers. Two are excellent, but a third has been atrocious. What feedback are you getting from your customers or the members of your associations? You are under privilege here; what you say is completely guarded under Parliamentary privilege. Are you able to name the good ones and the bad ones? I would like us to be specific

when we report, rather than speak in general terms and say some are good and some are bad. If you are able to tell us today, I would be grateful. Otherwise, you can write to us with the feedback you are getting from your patients and colleagues on who is good, who is bad and how well it is working.

Dr Christian Selinger: The feedback is mixed. Unfortunately, I cannot tell you the good ones because all of them have issues, just to varying degrees. Some homecare companies have had less complaints from patients and clinicians and some, which have attracted media attention lately, may have had more.

What is important is that it has real consequences for the patient when things do not work out. We have two major issues in performance at the moment. The first one is when we start medicines. At that stage, patients are in an active state of disease. They have lots of symptoms and their life is on hold for a period of time. The quicker we can start these effective medicines, the quicker we can get them back to their usual good state of health.

The problem is that it frequently takes six to eight weeks, sometimes longer, between setting up the initial contact with the homecare company and a delivery happening. That is an unacceptably long delay, and it has consequences. Patients have more symptoms and they function less well, but we also might have to give them steroids, which is an effective but very toxic treatment that does not help in the long term. These homecare medicines largely change the disease course in the long term.

Steroids are just a fire extinguisher, but one that is very toxic, so we try to avoid them. We sometimes have to do that simply to bridge the patient until the homecare company is ready. If we do not do that, the patients might, at least for conditions such as inflammatory bowel disease, end up in hospital with a completely avoidable hospitalisation. That is awful for the patient, but it is also an absolute waste of NHS resources.

A lot of services have tried to mitigate for this. Our infusion unit in Leeds is not meant to be involved in setting up self-administered injections at all, beyond reaching out to the homecare provider, yet we bring them into our infusion unit and we give them the first two injections. We teach them ourselves because we do not want our patients to experience that delay.

We are doing something that the homecare company is paid for but cannot deliver. That has consequences, because those specialist nurses are not available to deal with other patients. Similar things happen in other units. Either patients suffer or the NHS does mitigation, which has consequences as well.

The second issue where patients have problems and complain bitterly is repeat deliveries. As you can imagine, if you have a good response to therapy, it keeps you in remission and you are getting on with your life

but there is then a delay in receiving your medicine, it becomes a bit stressful. However, there are also physical consequences. If you are off the medication for two to four weeks, your symptoms will probably start to flare up again.

That might mean you have a less good time, but there are also longer-term consequences. When you have a gap in treatment, sometimes the body builds antibodies against those medications and they become ineffective. So, the medication that has worked for you becomes ineffective because we have not delivered the medicine on time for you. Then we need to switch therapy, and there are only a limited number of therapies available. That is far from ideal.

Our patients really struggle with getting deliveries organised sometimes. We have heard some harrowing examples of how patients have tried to contact the call centre of the homecare provider and not got anywhere. They then go to their specialist nurse services and complain to them. The nurses then get in touch with the homecare provider and they spend hours and hours—Ruth can attest to that—trying to get it sorted for the patient.

In the worst-case scenario, the patient can lose confidence in the whole NHS service, take themselves away from treatment and then suffer for a period before they come back and try it again. There is quite a lot of unnecessary suffering because the services do not perform to the level one should expect.

Sarah Campbell: I am really sorry to hear about your experiences, Lord Blencathra. You will understand, through this inquiry, that you are far from alone, unfortunately.

The feedback we are getting describes poor performance in a number of ways. As Dr Selinger said, there are lost and missing prescriptions, missed or failed drug deliveries, delays in processing of new patients, poor and disjointed customer service and a lack of accountability and sufficient oversight, as you have alluded to.

Judging performance in this sector is really tricky because there is a lack of publicly available data, which is something we would like to see change. Having met with a number of organisations involved in commissioning and delivery, the regulatory bodies around the sector and patient organisations and medical specialties, we are confident that the problems with homecare are broader than one medication, condition or provider.

Our members express concerns over the pattern of fragility and lack of resilience across the entire system. The problem is, the bigger the homecare provider, the bigger the ripple effect that is created when something goes wrong. We would not attribute issues to a single provider, but the market share of a company deeply affects the feedback we get. The bigger the provider, the more feedback we get about problems, but the issues are sector-wide and systemic.

Ruth Wakeman: Our understanding from people with Crohn's and colitis is that this is a widespread and long-standing issue. Some 62% of people with Crohn's and colitis told us that they have had problems with homecare services.¹ They describe a similar picture when it comes to getting set up on their medicines to start with, trying to arrange deliveries and deliveries not turning up or being cancelled at very short notice. There are issues with incorrect medicines and medicines of incorrect strength, and we have heard about out-of-date medicines as well.

There is a whole range of issues, and what makes it so much worse for patients is they cannot get hold of anyone. They cannot contact anyone at the homecare company. There are lots of tech-savvy people trying social media, email and phones. It is absolutely impossible to get through. When they talk to their clinical teams, the clinical teams cannot get through either.

Half of the Crohn's and colitis specialist nurses we spoke to told us that they are spending about half a day a week trying to solve these problems, and 12% said they are spending more than a day a week trying to sort out these problems.² It is pharmacy teams as well. One pharmacy service told us they were spending about 15 hours a week trying to resolve homecare issues for their patients. This is something that affects people of all ages in all communities. Half of the nurses who contacted us said that it has got worse in the last six months.

Lord Blencathra: It is not a resource that is available to most patients, but a middle-class bloke like me—I looked up the directors on Companies House and sent them a personal letter to their home address—was able to get action within 48 hours. It is not possible for everyone do that.

This question is more for Sarah Campbell. At the request of the BSR, I put down a Parliamentary Question asking who was in charge of sorting out a homecare provider if they failed patients. We were both shocked at the answer that no one is responsible. There is a whole NHS bureaucracy, in my opinion, that is hiding behind each other, with no one taking responsibility.

Can you make any recommendations today, or you can write in to us, on who or what should have the authority to penalise, cancel or transfer contracts from providers that are failing to provide?

Sarah Campbell: As we have described in our written submission, it is incredibly disjointed. You will have to forgive me; I will have to refer to my notes because it is extremely complicated. Different aspects of the

¹ 62% of people living with Crohn's and Colitis have said they experienced problems with their homecare services. Crohn's & Colitis UK Membership Survey May 2023, this survey had 711 respondents.

² 12% of nurses said that they spend a day or more supporting patients who have difficulties with homecare services, Crohn's & Colitis UK Nurse Survey May 2023, this is based on 96 respondents.

homecare business are within the purview of the CQC, the General Pharmaceutical Council and the MHRA. These regulators each have their own criteria for evaluation, which is again separate from the key performance indicators that homecare companies are expected to deliver on in their contracts.

Then there is the NHS, which has a separate system for monitoring performance in the sector through regional bodies and up nationally to the National Homecare Medicines Committee. These structures have no enforcement powers. When a company operating at a national level is failing to deliver services to local standards, the structures do not have enforcement that has any teeth if that provider is failing locally, across multiple regions or nationwide.

The issue is complicated by what I mentioned at the start: around 80% of homecare services are directly commissioned by pharma companies which hold their own contracts, their own enforcement mechanisms and their own KPIs with those providers. NHS trusts do not hold those contracts.

In terms of our suggestion for a recommendation, it is too disjointed. We need sufficient accountability in the system. We would like you to consider our recommendation in the written evidence: to review, streamline and establish clear lines of accountability that include greater enforcement mechanisms and align standards across those bodies.

Lord Blencathra: What is your experience, if any, of the Care Quality Commission investigating this? Are you aware that, since 2009, the CQC has prosecuted on 128 occasions but, as far as I can see from its spreadsheet, only seven have been NHS hospitals? Those accounted for four deaths in total. All the rest have been care homes. Apart from four deaths, the prosecutions have been on rather trivial matters. There has not been a single prosecution of big NHS hospitals responsible for all those hundreds of babies being killed.

What is your experience of the CQC investigating homecare providers? How far would you go along with my personal prejudice that it is a fairly worthless paper-tiger organisation, which likes to investigate the little guys but is scared to investigate the NHS because it is cosying up to the Department of Health?

Sarah Campbell: We started our campaign last September, as you are aware. We were hearing repeatedly by that point the concerns of our members about significant disruption across the sector. As a result, we met with regulators in England and Scotland. We were surprised to discover that the issues were not on their radar and they were not aware of significant numbers of patient complaints about homecare medicines delivery. It is fair to say that it was a blind spot, which we now hope will be addressed through the results of this committee's inquiry and the recommendations we have made.

Dr Christian Selinger: I have no direct involvement with the CQC.

Ruth Wakeman: From a patient perspective, it is just about someone taking accountability for these services. Patients are in the dark about who is actually responsible.

Lord Porter of Spalding: The moment is gone; I was going to ask a supplementary question on where Lord Blencathra was going. Given where he ended up, I do not want to follow him. I probably should declare an interest. It is not a financial one, one of the ones I normally have. I have had colitis for 20 years and I do not recognise the level of problems that you say most people have. Maybe the way I am looked after is just very lucky. I hasten to add that I was not here when I got colitis. I was just a patient to start off with, so it is not because I am on the red Benches that it is any better.

Q4 **Lord Shipley:** I found the written briefing we had very complicated to understand. Now I find it even more complicated. In fact, I find it chaotic. I ask you to comment on whether I would be justified in thinking that. In particular, I start to wonder why on earth we are doing it this way. Why has the system been set up in this way? Is there something in the history of it all that we must understand before we go any further?

Dr Christian Selinger: You are not alone in finding it complicated. I have been trying to get my head around the regulatory side, which is not my home turf, and I have struggled to understand who is responsible for what.

If I as a doctor do something wrong, there is an ultimate arbitrator, the GMC, that will hold me to account regardless of what my employer thinks. If a pharmacist does something wrong, there is the General Pharmaceutical Council. For nurses, there is the Nursing and Midwifery Council. Yet for these companies there seem to be several bodies and none of them is the ultimate arbitrator.

Historically, when these medicines came in, a lot of them were quite expensive to start with. As part of having to set up a delivery service, the pharmaceutical companies offered it as a package. That has brought it into the NHS without the NHS directly holding the contracts and therefore the power. The rest has developed a little bit out of this. There are only a handful of companies that work to any meaningful numbers in the business. Even if an NHS trust says, 'I want to commission my own services', there is not much to choose from unless you want to set up your own homecare company.

That is one of the problems. There is no true competition between the companies. You cannot look and see that one company delivers on its performance a lot better than the others. I do not know how we got here, but we definitely need to go somewhere else. There has to be accountability and transparency in performance so that both patients and clinicians can be assured that they will receive their drugs on time.

Sarah Campbell: We would agree with the 'chaotic' description. It has taken months of unpicking. We would be happy to follow up in writing

about any history that we have dug out about how we have got to where we are. Otherwise, we would not disagree.

Ruth Wakeman: I am hoping that a clear understanding of exactly what the mechanisms are is something useful that will come out of this inquiry. Where is the operational accountability? Where is the governance accountability? Where is the regulatory accountability as well?

Q5 **Lord Carter:** I should declare my interests. I am an adviser to the Royal Wolverhampton NHS Trust and I am also a director of Glenholme Healthcare, which provides long-term and other care.

I am trying to find somewhere where it works well. We have a two-tier market in the NHS now. We have people who pay privately and people who cannot. Is there a private market, first of all, and is that better served? In other words, are people able to leave the NHS, as they are for other services, and just buy them? In doing so, are they able to get a better service, or does it not exist at all?

Dr Christian Selinger: I do not think it exists at all. In theory, you can probably get those medicines privately rather than on the NHS, but the mechanisms would be exactly the same. Most of these medicines are beyond what individuals can afford.

Lord Carter: What I am really getting at is why this is so bad. We understand the regulatory issue—that has been made very clear—but there must be something structurally wrong. Is it inadequate funding? Is it that the pharmaceutical companies are not getting the right price from the NHS and are therefore squeezing the people who deliver it? Is it because the people delivering it are making too much money? What is wrong in the structure of this service?

Dr Christian Selinger: Locally, in Leeds, our patients have been complaining about it for the last 10 years. We have worked with different homecare companies at times, and improvement was possible. Staffing issues at the delivery and homecare companies have been raised several times. That includes professionals such as nurses and pharmacists but also delivery drivers and so on. There are more delivery drivers since the pandemic than before.

The processes, at least in some of the companies, are or have been pretty archaic.

Lord Carter: Is it a management issue, then? That is what I am getting at. Is it a management or a funding issue? Are these companies not sufficiently well run?

As a supplementary to that, presumably you go to international conferences. Your colleagues must talk about this. Have people solved this problem in Europe and other countries? We are not the only people with these long-term chronic conditions.

Dr Christian Selinger: I would not say they have solved the problem, but I did my fellowship in Australia in 2010. There, patients on the same drugs had a prescription from a specialist that they took to a community pharmacy, and the community pharmacy would very gladly deliver those drugs because they are paid a percentage of the price, and that was a much higher-value medicine than they usually dispense. In theory, there are other models. Whether they work better on a system scale, I cannot say.

Q6 **The Chair:** Is there anything about the drugs you are normally prescribing that would mean the community pharmacist could not do that?

Dr Christian Selinger: There is a little bit more to it, in that they are usually what is called biologic medicines that are injectables. They need to have what is called a cold chain, so they cannot be without temperature controls until they are handed over to the patient. Pharmacies can do that as well, but it was always considered far easier to deliver the medicine to the patient's home rather than the other way around, but it can be done by a community pharmacist. Technically it could be done, if there was the will to do so. Whether that would work any better, I would not want to promise, but certainly the current model is not the only model that is thinkable.

Q7 **Lord Laming:** I have found your presentation most helpful indeed. You made reference—there was also reference made to this in the paper—to this still being partially a paper-driven exercise. Is that a diminishing little bit of what happens, or is it still substantially paper-driven?

In this day and age, it just seems very odd that something as important as a prescription to a very vulnerable patient is corrupted, if I can use that word, by putting something in the post. The prescription is put in the post and it can be lost for six weeks, as you indicated in your introduction. Is this just a marginal thing or is it still quite substantiated?

Sarah Campbell: We are told by homecare companies that they are moving at greater pace towards an electronic system, which is something we would very much welcome.

We would draw to your attention the IT interoperability between the homecare sector and the NHS. The rollout of IT systems provides a fantastic opportunity for improvements for patients and clinicians, particularly around the role of integrated e-prescribing, but they have to be developed in a way that results in efficiencies and improvements for clinical staff across the board and patients themselves.

We would ask for digital platforms to be developed alongside the NHS and for them to interoperate with NHS systems that are also currently in use. There is a need to streamline the clinical process and not overburden it.

There are multiple homecare providers. At the moment there is no proposal for a single IT portal and no concrete proposals around an IT

interface between providers and the health service. A new approach that replaces burdensome paperwork could very quickly become a burdensome IT system without some kind of intervention.

As IT is developed across the sector, we need to guarantee that those solutions are aligned with the NHS and are of benefit to clinicians rather than being a burden.

Lord Laming: That is most helpful. I am terribly sorry that I have to leave. I am going to a meeting that will not be half as interesting as this one.

Dr Christian Selinger: If I may, there are attempts to make things better. One company has developed an app. One of our very tech-savvy patients struggled for an hour to get the app installed, and then they spent 45 minutes on the helpline with that company. In the end, their next delivery was arranged over telephone because they could not get the app to work.

As Sarah has pointed out, with five homecare companies, there is no point in there being five different interfaces. Most specialty services have at least two or three different homecare companies that they have to work with because different drugs are usually delivered by different companies.

Having several different portals that you need to register with, having to train on how to use them and having to remember all the passwords is just going to slow the process down. If the industry could come to one standard that would work with the same IT system, that would be extremely helpful.

Lord Prentis of Leeds: Could I just follow through on that question? When you look at some of the developments in the NHS, probably one of the more progressive developments has been the NHS app, which enables people who need prescriptions to order them without going to the doctors. It is done electronically. They can choose the place where they get the prescription from. It seems like this is a good development as far as primary care is concerned. Is it possible to learn anything from that that will enable a better service and solve the issues we are talking about?

Q8 **Lord Bach:** The role of pharmacies may be behind the last question and is certainly behind mine. We have read in the media that pharmacies are going to be asked to do much more in terms of primary health in the pretty near future. There is a role that pharmacies might play here to simplify the system and make it work better. I wonder whether you could say a little more about how possible that is likely to be, given the system in this country.

Sarah Campbell: I can briefly speak to that. I am afraid I do not have enough on the NHS app to make a significant comment, but we can definitely look into that and come back to you.

The Chair: If there is anything you feel would be useful, please let us have it.

Sarah Campbell: We will certainly come back to you. Generally, community pharmacies are closing at a great rate of knots. We have that issue. Linked to what Lord Carter was saying, there is a problem here around workforce more generally. There are only a finite number of pharmacists and nursing staff out there. The NHS is struggling to recruit; the homecare sector is struggling to recruit. There is potentially not the capacity within the system for other bits of it to be picking up the problems that are being created across the service. Dr Selinger may have more detail on pharmacy.

Dr Christian Selinger: Certainly, patients have brought up whether they could have had it delivered to their local pharmacy and picked it up there rather than having to attempt home delivery, which often does not work out so well. In theory, at least, that is feasible, but probably the logistics is something that people would have to look into.

The other issue, which Sarah pointed out quite nicely, is that they have a workforce issue. At least when it comes to pharmacists and nurses, we have a finite amount in the UK. We are already not supplying enough to the NHS to start with.

We expect the demand for homecare services to increase. We have seen in the fields of rheumatology, dermatology and gastroenterology that the use of those medications is increasing. There are more drugs becoming available due to the loss of some patents so they are becoming more affordable as well. The threshold for treatment is rightfully being reduced. If anything, the homecare medicines sector is going to be under more, rather than less, pressure in terms of demand.

Q9 Lord Willis of Knaresborough: I am having a fascinating afternoon listening to you. Thank you all very much indeed. Can I slightly move away? You have answered most of the questions I was going to raise. I am particularly interested in the future. I am particularly interested in virtual hospital care or virtual homecare. I call it virtual hospital care. That is really the one thing that can save the NHS from collapse, given the huge amount of impact that is going to come following Covid and the fact we are discovering new drugs and solutions, virtually on a daily basis, in one of the most brilliant research-based health systems in the world.

I have nothing specific to declare other than that I was until very recently the chair of the Applied Research Collaboration in Yorkshire and the Humber.

What I have found very difficult since the information came for this inquiry is trying to find any independent evidence to support the barrage of claims that there are of a highly inefficient and ineffective system. First of all, Sarah, do you know of any independent and quantified evidence that gives us the basis, as a committee, to say, 'This is the size of the problem that needs resolving'? Is that, again, something that has never

been considered?

Sarah Campbell: It is that lack of publicly available data that I mentioned before and the fact this has not been looked at a national level until now. It was looked at 10 years ago, but it is due to come up to date. The issues we are reporting are current. They are being reported by our members over the last three months from 48 trusts across England.

You mentioned virtual care. There is potential for virtual wards, but I would go back to the comment I made before about staffing. Changes in the system like that require a sufficient workforce, which we simply do not have.

We have our survey data; we have evidence from patients, which Ruth will want to talk to. What we do not have—this would be a good outcome from this inquiry—is a full-scale national review to get that sufficient and quantifiable evidence.

Lord Willis of Knaresborough: If you look particularly at parts of the US, Japan and parts of Germany, we are seeing that AI is becoming part and parcel of the solution. Rather than depending on putting more stress and problems on an existing workforce, which is not coping with the existing system, by using AI and very sophisticated IT portals we can deliver these things once we have had the initial analysis and recommendations from consultants. I do not see that happening anywhere in the UK.

I wondered whether you or any of your colleagues could tell me whether that is in fact happening. I am looking for solutions here rather than just emphasising the problems.

Sarah Campbell: Yes, absolutely. We have struggled to find any best-case examples to bring you, as was brought up before. Artificial intelligence, I am afraid, is not something I have come across, particularly with this particular sector.

The Chair: You do not have to take up the point about AI—do, if you want to—but, on the general issue of evidence, have either of you anything to add to that?

Dr Christian Selinger: We may be halfway there. Twenty years ago it would have been standard for patients with Crohn's or ulcerative colitis to receive infusions in a day unit setting. Nowadays probably a quarter of patients require that level of therapy, and the rest of the care is delivered in a homecare setting.

What has not really caught up with that is the way we organise that. Until about five years ago we had to fax prescriptions from one of the remaining fax machines in the hospital to a homecare provider because they did not accept anything else apart from an ink signature that was put through a fax machine. That was years after electronic prescribing for hospital inpatients had become a reality.

Some of the processes are difficult because within the homecare company sometimes the left hand does not know what the right hand is doing. It is like a black hole when the prescription goes in until the drug comes out. When you ring their call centre, they do not seem to know where it is in the process. That creates an awful lot of work.

The drug service within the hospital is spending 15 hours a week resolving these things; the IBD nurse is spending a day a week trying to resolve these things. If those things are not needed anymore because we have a well-functioning system with easily accessible data, the existing workforce can be put to much better use. Frustrations will go down, and we will have happier patients and a better-performing workforce.

At the moment, we are working in very difficult circumstances. I have no doubt that homecare providers are struggling to retain and get the staff they need, but, for them to function well, they need to address that and look forward. If there have been any suggestions that things have improved, certainly from the feedback from clinicians we have had, the matter is getting worse or is, at best, in a steady state.

We have had issues with homecare providers going back seven, eight or 10 years. They have temporarily improved, but they have always got worse again. With the demand we anticipate, we really need to future-proof this industry and get it performing rather than carrying on with the haphazard way it is performing at the moment.

Ruth Wakeman: I just wanted to add a few points about the evidence. We have heard from patients and from Crohn's and colitis specialist nurses. We asked patients and 1,000 responded in three days. They told us stories about needing surgery due to failures in homecare services; they told us about going into flares, which impacts on their ability to lead their lives and is also incredibly distressing and painful for them; they told us about being put on courses of steroids; they told us about their choice of drugs being reduced because, if they miss doses, sometimes the drugs do not work anymore.

We are also hearing this from nurses. Again, nurse specialists told us that this is a real problem. One of the issues is that there is an underreporting of complaints. Specialist nurses said to us that on average they will probably do three homecare complaints in six months, but the true scale of that is that for every official complaint there are 10 they are not reporting. They are saying, quite frankly, that after spending half a day chasing up problems, they do not have time to take away from patient care to sit, fill in a bunch of forms and go through the very laborious complaints processes.

Evidence is a really good point. It is really unclear. There is no data in the public domain. There is no information. We could not find out how many patients with Crohn's and colitis are receiving homecare medicines, for example. We could not find out the size of the market.

The Chair: That is fairly basic information, is it not?

Ruth Wakeman: Yes, exactly.

Lord Willis of Knaresborough: Yes, it is such a fundamental issue. Unless you have that data, unless it can be objectively looked at and certified, it is difficult to make the sort of recommendations this committee needs to make in order to get this incredibly exciting opportunity made into a reality.

Can I come back to Dr Selinger? I was particularly struck by the comments you made about introducing at Leeds some of the conditions and treatments before they were sent out to home services. That enables the system to work much more effectively. It seems to me that that is exactly how it should be. These should not be separate silos that operate in separate units; they should in fact be part and parcel of a totally integrated system.

I just wonder whether there is opposition to that within the NHS. Is it simply because you just do not have the time or the energy to be able to deliver that as an integrated service?

Dr Christian Selinger: Certainly going back to the intravenous infusion, we do not have the staff or even the physical space to deliver infusions for everybody who is getting home injections at the moment, even if all the patients wanted that. One of the reasons for having more and more homecare delivered is that we cannot physically get all the patients who require these therapies into our infusion units. Neither is that desirable for patients, from the feedback we receive.

Could the NHS in itself do it better without the homecare companies? Certainly not without a massive investment in staff, IT and organisational support, no. In theory we could do that a lot better. The homecare companies could also work much closer with the NHS, be much more transparent about their own performance and help us work together with them a bit more.

The biggest issue, as Sarah outlined at the start, is that for 70% to 80% of patients on those therapies the contractual obligations are between the homecare company and the pharmaceutical company. The NHS is the innocent bystander in a sense. It has some expectations but few enforcement mechanisms. If there were a direct contract, you could probably enforce that a lot more, but then you would end up in a situation where you need to find a competitor that can perform better, which is tricky as well.

The triangular relationship between the homecare company, the pharmaceutical company supplying the drug and the NHS paying for all of that does not work out very well. We need to remember that the pharmaceutical company may pay the homecare company, but in the end the NHS pays a composite price and indirectly pays for it as well. It is the taxpayer paying for it, but at the moment they are not getting what they should get in return.

Q10 Baroness Stedman-Scott: When these companies agreed to provide these services, did they say, 'This is what we can do', and we contracted with them, or was it the case that there was a business model that they said they could deliver to and we did the contract? If it is the former, does that need to be changed to get some consistency across the board?

Sarah Campbell: I will double-check and follow up with you, but I would imagine that there is a service specification. There will be a tender exercise, and those services will be coming with a proposal for how they would deliver that service and the KPIs they would need to meet as a result before contracting. We can get further detail.

Baroness Stedman-Scott: I will follow on from there with a basic question: who is reviewing their performance on a quarterly basis? Who is doing something, or not, about the companies that are doing well and those that are not?

Sarah Campbell: This goes back to our point about the disjointed system because different people are being held to different standards, measures and indicators. It is the regulatory bodies, contract holders and national bodies, but they are not singing from the same hymn sheet.

Baroness Stedman-Scott: I have no interests to declare, other than my dearest friend has Crohn's and I have spent hours with her over there and all over the place. She has had exemplary care.

The Chair: Just following on from that, what percentage of patients with Crohn's, for example, receive homecare roughly?

Dr Christian Selinger: At the moment, for those on advanced therapies, I would imagine 70% to 80% is homecare. It is probably 40% of the patients with Crohn's disease at any one time and probably about 15% with ulcerative colitis. We are probably talking about a quarter of patients with Crohn's disease who are on drugs that are delivered by homecare companies.

The Chair: That reflects your membership, presumably.

Dr Christian Selinger: There is variation between different hospitals, but this is roughly what the membership reports back to us and what we have seen in national audits.

Baroness Stedman-Scott: If one were to be able to magic up the things you have said would make the difference, like having a consistent system, enforcement and everybody operating the same thing, would the companies that currently do this cut and run? Would it cause a massive disruption to patients or, on the other side, would it open up a better service for the people that can deliver? That is subject to staffing and money. Would it make it better for patients?

Sarah Campbell: It is an interesting question. I cannot really speculate on what they would do.

Baroness Stedman-Scott: What is your view?

Sarah Campbell: The profit margins are relatively small. As I said before, we do not have an example of where it is working well. I do not know who would move into the market to do it any better.

Baroness Stedman-Scott: It is something to watch.

Q11 **Lord Carter:** I suppose this is what we are really trying to get to. What policy changes should this committee be recommending? In that, where should the accountabilities sit? In a sense, we are having this debate about data. It seems like there is plenty of data, but actionable data appears to be very hard to collect. I am quite surprised. Without building an IT system that integrates all of this, presumably you cannot pick it up.

As a second part of that, perhaps somebody would like to say where they think the accountability for IT sits at the moment and maybe where it should sit going forward. Perhaps you could kick off with your general recommendations.

Sarah Campbell: From a patient perspective, patients are relying on these services. When they go wrong, they do not know who to turn to. They cannot go to their GP. The specialist services at the hospital cannot help them. It seems completely impenetrable. They have no way of raising concerns.

There are, we understand, KPIs for homecare services, but performance against those KPIs is not publicly available, as far as we know. For many patients, there is no choice. If they need a certain medication, they can often only access that through a homecare service. There is no choice for patients.

Patients would prefer this to be working well. They want to be receiving their medications at home rather than traveling to hospital. It seems completely unclear how to raise concerns, how to raise complaints and then who is accountable for those service failures.

Lord Carter of Coles: Does the contract with these suppliers not specify this? Is there a KPI that says, 'You must answer the phone in so many minutes'? Have any of you seen these contracts?

Dr Christian Selinger: I am not sure about call centre responsiveness, but there definitely are targets in there for how long it should take for set-up and that deliveries should be on time. The problem is that, for the clinical services, these performance indicators are not transparent or not made available. That is also true about when they are not met. One of the companies wrote to us earlier this year to say they are currently under difficult circumstances and they cannot deliver the target for the next few months. There was no recompense.

Lord Carter of Coles: These are secret standards, are they?

Dr Christian Selinger: They are not secret.

Lord Carter of Coles: You cannot find them.

Dr Christian Selinger: Nobody tells us whether they are achieving them. The target is public, but whether it is achieved is not necessarily made public.

Lord Bach: There is no point in the target.

Baroness Stedman-Scott: Yes, exactly. That is my point.

The Chair: Does anyone collect this data? It is not collected and kept secret. It is not even collected in a way that is helpful.

Dr Christian Selinger: I do not know, but I would assume that the companies themselves keep their target data.

Sarah Campbell: I am being told it is the National Homecare Medicines Committee that would collect that. On the policy point, we are asking for a national review of homecare services in England that is equivalent to the one we have been promised in Scotland by the Chief Pharmaceutical Officer.

Our recommendation is for a holistic review that would cover the eight areas detailed in our written evidence: refreshing the current standards and codes of practice; streamlining accountability and enforcement; improving communication and the customer service culture across the industry; reviewing the complaints system; introducing IT operability and e-prescribing; addressing shortages and vacancies and adding to the long-term workforce plan that is currently under way; and committing to public performance data.

Lord Carter of Coles: That is quite a list, is it not?

Sarah Campbell: It is quite a list.

Lord Blencathra: That is the guts of our report.

Lord Carter of Coles: Just on that, does the accountability for this lie with the Chief Medical Officer in England?

Sarah Campbell: It lies with the Chief Pharmaceutical Officer.

Lord Carter of Coles: Presumably, the Chief Pharmaceutical Officer reports to the Chief Medical Officer.

Sarah Campbell: Yes.

Lord Carter of Coles: The person we need to ask is the Chief Medical Officer.

The Chair: Who could be the driving force for this change?

Lord Carter of Coles: We are trying to get to the top of the pyramid. Could you check that for us?

Sarah Campbell: We will. As I say, in Scotland it is the Chief Pharmaceutical Officer who has committed to that national review.

Lord Carter of Coles: We have the Chief Pharmaceutical Officer for England coming, do we not?

The Chair: Yes, we have.

Lord Porter of Spalding: It does not seem that difficult a problem to fix, does it? If we are paying for the service as taxpayers, we demand the minimum service standard we want, and no contract gets let to anybody who does not agree to that contract. The basis of the contract could say, 'We will monitor these figures, and you will collect the data for us. You will put it on this platform'.

Who is stopping that from happening? This cannot not have happened because nobody has got around to it. Somebody must be stopping it from happening. Whose interest is it in to have such a chaotic system that stops anybody getting the service we pay for as a country.

Baroness Stedman-Scott: Whose interest is it in not to make it better?

Lord Porter of Spalding: Somebody must be stopping it because it is not a hard problem to fix.

The Chair: Yes, unless it is just not on anyone's agenda for some odd reason.

Lord Blencathra: It is bureaucrats keeping their heads down. If a pharmacist pops up and stops it, someone else says, 'You have no authority to do that'. No bureaucrat wants to take it on.

Lord Porter of Spalding: There must be minimum standards in the contracts for anything the health service buys. As the taxpayer, we must have somebody in an office up the road sitting there saying, 'You cannot have one of these contracts unless you meet X, Y, Z'.

Sarah Campbell: It is the disjuncture. No single body is taking responsibility for the system as a whole. This goes back to what I said earlier, essentially.

Q12 **Lord Shipley:** The question that was posed originally was about complaint, enforcement and accountability mechanisms. I just wondered whether you could say something about harm. We have talked about complaints, difficulties and surveys done where patients complain and say they have problems.

Can we take it a step further? Can we look at harm? Do you have any quantification of how much harm has been done to how many people because this system does not work? This might relate to the work of an ombudsman, but it could go further than that in terms of legal action. Has anyone ever attempted legal action for harm? Are they entitled to do so? What has the outcome been? I am just after any evidence you have that will assist us in forming a clear view.

Dr Christian Selinger: That is an interesting point. Clearly, this is what we are most concerned about. The short-term harm may be reversible or there may just be a period where they flare up, as Ruth described, where a patient has pretty insufferable symptoms. There are also sometimes long-term harms. If a disease goes completely out of control and a patient needs surgery, that is irreversible and life changing.

It is very difficult for us to put figures on that. There are no nationally available figures where we can easily say, 'Hang on. This happened here because of X'. In terms of individual reports, we have those about all the services. As Ruth has said, there are individual cases we can relate it to. If you were asking whether we have more than cases here and there, we do not have evidence of harm on a solid basis.

Q13 **Lord Blencathra:** Lord Shipley, I will forward you a link to a Care Quality Commission report that indicated that one company was responsible for 9,300 patients suffering harm. Some had to be readmitted to hospital because their drugs were not delivered.

Lord Carter, it is not a matter of the phone not being answered in three rings. You get into this vicious circle where you cannot email them back because you get a noreply.com message. You have to dial an 0800 number, and the 0800 number will tell you, 'I am sorry, our lines are busy. Why don't you email us instead?'

My real question was to follow up on what Dr Selinger said. Some medicines have to be chilled. One of the ones I get has to be chilled, and it has to be stuck in the fridge when I get it. Another one I get is about as harmful as aspirin. It is great for me and others who get it. Do you have any experience of medicines that do not need a special courier to deliver? If a drug team intercepted them, they could not grind them down, smoke them or inhale them. They are no good to them.

Could they be sent through the post instead? Could there be a type of special delivery where the companies would still be in charge of the delivery but they could post them instead.

Dr Christian Selinger: There are drugs that are tablets that fall under this category. It is largely because they are the same therapy area, because they are high-cost drug items and because they are coming from secondary care prescribing rather than primary care prescribing. These are tablets. There is no temperature control; there is nothing special about them. At the moment—and this is a growing market—they are going through homecare services.

There is nothing to suggest that this could not be organised differently or that these could not be shipped by non-specialists, but, probably because there are other drugs in the same field that require temperature control, the area has just evolved that way. As that market is growing, it would certainly be sensible to consider whether the homecare model we have at the moment is the right way to deliver these drugs.

The Chair: They are putting it into a failing system.

Dr Christian Selinger: Yes.

- Q14 **The Chair:** Before we finish, I just wanted to go back to something. I think I know the answer, but I just want to make sure we have asked for our evidence. You have said that this service goes back a long time and the trend is that you have always had complaints going back over 10 years.

For instance, Dr Selinger, you are based in Leeds, but I know you have a national role. Is it the same throughout the country? I will ask the same of Ruth and Sarah. Can you say a little bit about geography and a little bit about the age of the patients who tend to be affected? That would just help us as evidence in our report.

Dr Christian Selinger: Inflammatory bowel disease affects children from as young as three to five years old to patients in ripe old age, but the predominant age of diagnosis is between 15 and 35. It affects many patients for a long time in their life. It affects many patients during their reproductive years or during schooling and university. It is really quite a critical time in their life. The better you control their disease, the more they hopefully can fulfil their ambitions in life.

With other diseases in rheumatology, it is slightly different. There are some that are juvenile onset and some that have a later onset in life, but it is a huge spectrum.

In terms of geography, at least for the diseases I look at, it is the same all over the UK. There is probably a slight predominance the higher you go up in the north and Scotland, where it is slightly more than in the south, but these are nuances. It affects many people across the country. It is not like you have fewer problems in rural communities than in urban communities. It gets harder and harder to deliver care in rural communities, but the same percentage of patients are affected by it.

Ruth Wakeman: In terms of geographical groups, we are a UK-wide charity and we hear concerns across the UK. It is interesting that in Scotland the Chief Pharmaceutical Officer has launched their review as well. Nurses also tell us that this is a widespread problem.

Some people who may be particularly affected are those with temporary addresses. The system is so cumbersome that people cannot change their address. We have heard of students who have not managed to get their medication delivered to their university town, and they have had to travel home to pick up their medication. That is before you think about people with no fixed address and the problems they must be encountering.

Our understanding is that it is widespread geographically and demographically, across ages and genders. It is a problem that is affecting anyone who relies on these services.

- Q15 **Lord Prentis of Leeds:** A couple of things have occurred to me while I have been listening to much of the debate. In most parts of the NHS and health services, and even care services, where there are substantial

problems, there are units that seek to improve the provision of services. In education, you have Ofsted. Is there nothing within the whole of the healthcare system that looks at how they can improve this service to patients rather than just leaving it the way it seems to be at the moment?

The other thing that occurs to me is about the contract itself. Are these companies being paid for each delivery or is it an annual fee to provide a particular service? I understand the difficulties, but would it be possible to look at any of these contracts? The failure could well be in the contracts themselves.

Sarah Campbell: I can take the issue about clinical improvement. Clinicians do have an important role to play in fixing homecare service issues. Our members definitely stand ready to do so. They have engaged significantly with this inquiry and our campaign to date.

We have to be clear that clinicians are not ultimately responsible for this system, this £2.1 billion industry. At the moment they are heavily distracted by having to deal with the concerns and problems we have outlined today. That is taking away significant time from clinical care. They are ready to help; they are ready to support. They desperately want it fixing because, when it works well, it is a fantastic utility. Neither the NHS nor our clinical teams are singularly responsible for fixing this.

Chair: We are very grateful for how you have started us off. It was very good. If there is anything you or your teams think of or if you think, 'We did have a little bit of evidence on that', please send it to us. If it is in written form, we will be able to have it as printed evidence for our inquiry.

We are sorry that you are having such a difficult time. We appreciate that, for all of you, this is a relatively small part of your jobs, is it not?

Sarah Campbell: It is.

Chair: You are doing other things as well. You are not working full time on trying to make the homecare medicines system work. It just feels that way on some days of the week. We are very grateful. We have all found that very informative.