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Public Bill Committee

HEALTH AND CARE BILL

Thirteenth Sitting

Tuesday 19 October 2021

(Morning)

CONTENTS

Clauses 79 to 85 agreed to, some with amendments.
Adjourned till this day at Two o'clock.

No proofs can be supplied. Corrections that Members suggest for the final version of the report should be clearly marked in a copy of the report—not telephoned—and must be received in the Editor’s Room, House of Commons,

not later than

Saturday 23 October 2021

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The Committee consisted of the following Members:

Chairs: † MR PETER BONE, JULIE ELLIOTT, STEVE McCABE, MRS SHERYLL MURRAY

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| † Argar, Edward (<i>Minister for Health</i>) | † Owen, Sarah (<i>Luton North</i>) (Lab) |
| † Crosbie, Virginia (<i>Ynys Môn</i>) (Con) | † Robinson, Mary (<i>Cheadle</i>) (Con) |
| † Davies, Gareth (<i>Grantham and Stamford</i>) (Con) | † Skidmore, Chris (<i>Kingswood</i>) (Con) |
| † Davies, Dr James (<i>Vale of Chwyd</i>) (Con) | † Smyth, Karin (<i>Bristol South</i>) (Lab) |
| † Double, Steve (<i>St Austell and Newquay</i>) (Con) | † Timpson, Edward (<i>Eddisbury</i>) (Con) |
| † Foy, Mary Kelly (<i>City of Durham</i>) (Lab) | † Whitford, Dr Philippa (<i>Central Ayrshire</i>) (SNP) |
| † Gideon, Jo (<i>Stoke-on-Trent Central</i>) (Con) | Williams, Hywel (<i>Arfon</i>) (PC) |
| † Higginbotham, Antony (<i>Burnley</i>) (Con) | Huw Yardley, Sarah Ioannou, <i>Committee Clerks</i> |
| † Madders, Justin (<i>Ellesmere Port and Neston</i>) (Lab) | |
| † Norris, Alex (<i>Nottingham North</i>) (Lab/Co-op) | † attended the Committee |

Public Bill Committee

Tuesday 19 October 2021

(Morning)

[MR PETER BONE *in the Chair*]

Health and Care Bill

9.25 am

The Chair: Before we start, I have a few notices. Welcome to Committee Room 14. Please stand to catch my eye because this is such a long room, although if you are doing anything naughty at the back I will see it. I should say that today is my birthday, but wishing me a happy birthday will get you no advantages. Electronic devices should be put on silent mode. No food or drinks, except water, are permitted during the sitting.

The House encourages Members to wear masks when they are not speaking and to give one another space when seated and when entering and leaving the room. Thankfully, in this Committee Room that is easy to do. *Hansard* colleagues would be grateful if Members could email their speaking notes to hansardnotes@parliament.uk.

Clause 79

INFORMATION STANDARDS

The Minister for Health (Edward Argar): I beg to move amendment 117, in clause 79, page 69, line 15, leave out “services” and insert “care”.

This amendment has the effect that information standards may be set for public bodies that exercise functions in connection with the provision of any health care in England, and not simply NHS services.

The Chair: With this it will be convenient to discuss the following:

Government amendments 118 to 121.

Clause stand part.

Edward Argar: It is a pleasure to serve under your chairmanship, Mr Bone. As a member of the Government, I am well aware that seeking to curry favour with you in the Chair is a futile task, but none the less I wish you a happy birthday.

The amendments ensure that the drafting of the clauses covers all healthcare, whether delivered by public bodies or by the independent sector on behalf of the NHS or not, and that the relevant persons are captured by the requirement to comply with information standards. Those are matters of technical detail, and ensure that the changes made by clause 79 are coherent and consistent.

Amendment 117 makes minor changes so that information standards can apply to public bodies that exercise functions in connection with the provision of healthcare in England. It ensures that information standards can be applied to public bodies, even if the healthcare is not provided as part of the NHS. Similarly, amendment 118 ensures that information standards can apply in the processing of non-NHS and NHS healthcare information.

Amendments 119, 120 and 121 make consequential changes as a result of the previous amendments. Without those changes, there could be uncertainty about whether information standards can be applied to healthcare information generated outside the NHS. Without the

amendments, we might not be able to ensure that data relating to NHS services—such as data about services provided in private patient units or by independent sector providers—flows through the system in a standardised way so that it is always meaningful and easy to understand for any recipient or user.

Clause 79 amends the Health and Social Care Act 2012. It allows the publication of mandatory information standards relating to the processing of information, including its transfer, collection and storage. Health and adult social care providers must currently have regard to information standards, but the clause would require providers to comply with them. The clause allows for the application of mandatory information standards to private providers as well. It requires regulations to be made about procedures for creating information standards. The clause also includes a power to require information from providers for the purpose of monitoring compliance with information standards.

The measures will help ensure that information flows through the system in a standardised way so that it is easily accessible and useful, and they will help to ensure the security of that information when it is processed. Given that publicly funded providers are already required to have regard to information standards, the clause will cause minimal disruption to compliant providers but will enhance the Department’s ability, on behalf of the public, to deal effectively with cases of non-compliance.

By applying information standards to private providers, the clause aims to improve the experience of patients who move between publicly and privately funded services by their own choice, such as individuals who choose elective surgery by a private provider. It does that by enabling the setting of standards that encourage the frictionless movement of information between those providers, with the aim of supporting timely and appropriate patient care decisions.

We consider the clause a crucial enabler for the creation in its broadest sense of a modern health and care service whose systems are integrated and responsive to the needs of patients and users. I commend it to the Committee.

Alex Norris (Nottingham North) (Lab/Co-op): It is a pleasure to resume proceedings on the Bill with you in the Chair, Mr Bone. I would extend birthday greetings to you, but I know that Tom Brady and the Tampa Bay Buccaneers are already giving you all the joy that you need at this time of the year.

The Chair: That has more influence.

Alex Norris: I thought that might get more traction with you.

I also take the opportunity on behalf of Opposition Members to pass our sincere condolences to Government Members and to pay tribute to our friend Sir David Amess. He was a wonderful man: funny, kind and caring. I say that now because my final conversation with him was about the Bill, which precluded me from joining him on a trip. He commended me on my diligence but also cautioned me not to work too hard. I will always remember that; it was classic David.

As the Minister said, we have reached the data part of the Bill. It is important for everything we talked about in part 1, because all the new cultures that we seek to foster will fall over if the data does not work and, as he

said, flow freely back and forth between organisations. At the end of the day, ensuring that data can port between different organisations is our problem to solve, not that of the patient or the individual. Therefore, if we are to have properly joined-up care, it is vital that those who provide care have a full sense of who they are caring for and what is needed.

I will not cover the Opposition's really good amendment to the next clause, which would improve it further, until we get to it. In that spirit, we do not intend to divide the Committee on this group of amendments or on the clause more generally, but I have a couple of points to address, which I hope the Minister might come to in his summing up.

On the clause in general, the Opposition support putting the entire health and care system on the same footing for information standards. As we heard in oral evidence, one of the major blockers is the myriad data systems used across the health and care landscape, many of which cannot talk to each other. When I was an adult services portfolio holder in my local council, I saw how hard it was sometimes even for council systems to talk to each other—I do not know whether that was remarkable or inevitable—never mind systems across different organisations and, in this case, the public, private, and community and voluntary sectors. That is a real challenge. I do not think we can remove that completely—systems may look different because of their different purposes—but there must be some attempt to standardise.

The Opposition do not oppose the clause, but proposed new section 6B in subsection 2(c) allows organisations to opt out—we might want organisations to be able to do that in some circumstances—and proposed new section 6C provides that regulations will cover when that is allowable. However, it is hard to know whether the clause will work until we have seen whether the regulations are strong enough and set a high enough bar on opting out. Will the Minister confirm that the measure allowing for opting out will be very much exceptional and that we will not see any nonsense about commercial confidentiality? We want data to flow across sectors, and that confidentiality has traditionally been one of the barriers to that.

Let me turn to Government amendments 117 and 118, which will expand the scope of the organisations covered. That is good. If we are to share data between social care and more traditional healthcare services, that includes a big landscape of non-NHS providers and perhaps even non-local authority providers, and it is right that information standards should be aligned. There must be a common basis on which to build. The Minister said that in general most organisations are probably already in that space and paying the due regard that they need to, but I fear that these things will be easier in concept than in execution. I am keen to learn what assessment the Minister and his officials have made of how ready the disparate providers in this landscape are to meet these new requirements, whether he thinks there will be a transition period, and whether providers will be helped to do this. Otherwise, the implementation of this strong concept in the Bill will not work. I hope the Minister can address that.

Edward Argar: May I put on record my gratitude to the hon. Gentleman for his kind words about our late colleague? I suspect that the Health team and the shadow

Health team will also speak of him in oral questions in the Chamber in a little while. The hon. Gentleman's anecdote was all too typical of Sir David and his approach to these things. I think the last time I spoke to Sir David was at our party conference; I had to do something on the platform, and he seemed mildly bemused by the fact that I was rushing off to have my make-up done before I went before the cameras. He then insisted on posing for a photograph with me. It was typical of him. We all miss him terribly in this place, as of course, most importantly, will his wife.

I am also grateful to the hon. Gentleman for his support, in broad terms, for clause 79 and the Government amendments. He is absolutely right about the importance of data flowing freely and safely for the benefit of patients. That is why the clause strengthens the wording of the Health and Social Care Act 2012, so that it says “must...have regard to” and “must...comply with”.

The hon. Gentleman asked a number of questions. First, he talked about the option of opting out from regulations. I can offer him reassurance on that; yes, I hope that its use would be exceptional, rather than the rule. Our assessment is that there is already widespread compliance with what we are seeking to do here, but as he rightly says, we have to make sure that we have as robust a framework as possible, because it is up to us to make this work for the patient, rather than their having to work their way around a challenging framework.

The hon. Gentleman's final point was about the burden of execution. He is absolutely right; as we all know in this place, and from our previous careers in local government—we talk about this a lot—something can look immaculately thought-through and put together on paper, but when we hit the reality of practical implementation, there can be significant challenges. It is not our assessment that there will be significant burdens or challenges with implementation; I go back to my point that our understanding is that the vast majority of these requirements are already adhered to. However, I am happy to keep the matter under review, and to make sure that we tweak the implementation if we need to, and are sensitive to the reality on the ground.

Let me put a bit more flesh on the bones on the subject of the waiver—the opt-out, as it were—as we may touch on the subject when we come to the hon. Gentleman's later amendments and in subsequent clauses. The thinking behind the waiver is that there may be circumstances in which an organisation feels that it genuinely cannot meet a published information standard that applies to it. That is why there is the waiver power. It could apply to use it, but that request would have to be considered very carefully by officials before it was granted.

I hope that I have given the hon. Gentleman some reassurance, but he knows, I hope, that I seek to be pragmatic in much of what I do, and in the implementation of the provisions, I will seek to apply a degree of common-sense pragmatism.

Amendment 117 agreed to.

Amendments made: 118, in clause 79, page 69, line 21, at end insert—

“(aa) in subsection (3), for ‘services’ substitute ‘care’;”.

This amendment makes it clear that the Secretary of State's power to set information standards extends to information concerning health care other than NHS care.

[Edward Argar]

Amendment 119, in clause 79, page 70, line 2, at end insert—

“(d) in subsection (7)—

(i) at the appropriate place insert—

‘health care’ includes all forms of health care whether relating to physical or mental health and also includes procedures that are similar to forms of medical or surgical care but are not provided in connection with a medical condition;”;

(ii) omit the definition of ‘health services’.”

This amendment is consequential on Amendments 117 and 118.

Amendment 120, in clause 79, page 70, line 29, at end insert—

“(3A) In section 251C (continuity of information: interpretation)—

(a) after subsection (6) insert—

‘(6A) “Health services” means services which must or may be provided as part of the health service in England; and for that purpose “the health service” has the same meaning as in the National Health Service Act 2006 (see section 275(1) of that Act).’;

(b) for subsection (7) substitute—

‘(7) Adult social care’ and ‘public body’ have the same meaning as in section 250; and ‘processes’ and ‘processed’ are to be read in accordance with the meaning of ‘processing’ in that section.” —(Edward Argar.)

This amendment is consequential on Amendment 119.

Clause 79, as amended, ordered to stand part of the Bill.

Clause 80

SHARING ANONYMOUS HEALTH AND SOCIAL CARE INFORMATION

Alex Norris: I beg to move amendment 109, in clause 80, page 71, line 15, at end insert—

“(4A) Before the power in subsection (1) may be exercised, and every five years thereafter, the Secretary of State must review, and lay before Parliament a report of that review, the possibility of combining the exercise of that power with the exercise of the powers under which—

(a) the General Practice Data for Planning and Research programme, and

(b) other data-sharing programmes are run.”

I am moving this amendment in my name and those of my colleagues. There has been some disappointment that on part 1 of the Bill we have not been able to move the Government particularly far from what was originally presented in the Bill. As has been said a number of times, this Bill ought to drive integration in health and care services, but instead we really have a reorganisation Bill, with a promise from the Prime Minister to return with an integration White Paper in due course—when presumably some configuration of all of us will come back and do all this again. It is hard to think that we have not left some opportunities on the table, so I hope we can do better on parts 2 to 5 of the Bill, and I do not think there is a better place to start on that than amendment 109, which would significantly help the Government with an issue that they have been struggling with for more than a decade.

It is obligatory for Health Ministers and shadow Health Ministers to start by saying that data saves lives, and it does. It tells us what is happening in our communities

and our country and how we may need to change services to meet the needs of populations. But if it is done right, it can also tell us what will happen in the future and what future needs we will have to meet. For the purposes of designing health and care services, that is golden information. It gives us the chance to get ahead of the curve, to make good early investments and to avoid dreadful workforce gaps, which we are seeing at the moment and which have been created over the last decade.

We are fortunate that there is no country in the world better set up for high-class use of data than ourselves. We have a single health system in each of the four nations covering our entire populations. Of course, our data is spread over more places than simply NHS databases. If we can get it organised, we ought to have the most rich understanding of our population’s health and of the outlook for the future. What an extraordinary gift that is, but we are not using it effectively enough at the moment and we can do much better.

I remember, early in my stint as shadow Public Health Minister, meeting a group of dentists, one of whom said to me that they can not infrequently recognise the signs of certain eating disorders by the impact that frequent vomiting has on the back of a person’s—in these cases, generally a young person’s—teeth. They found it hard to understand why they had no idea whether anyone else who provided care for that individual, or perhaps even the individual themselves, knew that that had happened, because they had absolutely no broader healthcare information about the person. Of course, there are important circumstances in which we need to create firewalls to protect privacy, and we would want people to have only the information that they needed to do their job properly, but in this case the clinician felt like they were flying blind and unable to provide the very best care for this person as a whole person rather than caring just for the teeth of the person.

As an Opposition, we want to see data used well, wisely and in an integrated manner, and if there has really been only token integration in part 1 of the Bill, why not see the real thing in part 2? As I have said, the history here for the Government is chequered. Only this summer, through the General Practice Data for Planning and Research programme, the Government sought, with a characteristic, I might say, lack of touch, to grab all the data from England’s GPs without explaining to patients why they wanted it, what they would do with it, who would use it and who would not use it. Again, it feels as if it is more than a three-word slogan: not enough time was taken to explain this, and the result was entirely predictable.

According to a survey done by Which?, 55% of people had heard of the scheme and, of those who had, 71% felt that the NHS had not publicised the scheme well. Of those unaware of the scheme, nearly 40% stated that they would now be likely to opt out of it. Fifty per cent. of the respondents who were aware of the plans said that they had heard about them through news or social media rather than official sources. Forty-two per cent. said that hearing about the scheme made them trust the NHS less—that was a particularly startling finding. And nearly one third of those who knew of the scheme and had opted out of it had found the opt-out process overly complicated. What a mess. In the end, we saw 1.4 million people opt out, despite how

hard it had been made to do so, and the plans were soon punted into the long grass, to return at a date not specified.

This is a real hammer blow for the confidence in how the state and the country handle data. These were the headlines on 13 and 14 October alone. The *Bracknell News* had, “Thousands of people in Bracknell Forest have opted out of sharing their medical records”. The *Somerset County Gazette* had, “MORE than 10,000 people in Somerset West and Taunton have opted out of sharing their medical records”. The *Lancashire Evening Post* had, “Thousands in Preston block bid to share medical records”. The *Wirral Globe* had, “Tens of thousands of people in Wirral have opted out of sharing their medical records”. The *Bolton News* had, “Nearly 20,000 Bolton patients opt out of sharing their medical records for research.” There were similar headlines in the *Shields Gazette*, *Hemel Hempstead Gazette*, the *Hartlepool Mail* and more. If it were not so serious, it would be funny.

9.45 am

Each of those headlines is another setback for confidence in individuals’ data and its handling by the state. They go into people’s inboxes or browsers across all those communities and undermine the case for the better use of data. This episode should be looked on with real sadness and frustration. After significant opposition from Labour Members, the British Medical Association, the Royal College of General Practitioners, patients and campaigners, the process is now in mothballs, perhaps never to be seen again.

I talked to a journalist after the pause was announced, and they said to me, “Alex, that was a big win for you guys, eh?” I think they were surprised when I said that, at best, it was a pyrrhic victory, but in reality it was a loss for everybody because we will not now be in a position to use our data to its maximum effect. Even worse, the Government had tried the exact same thing eight years previously and failed in precisely the same way. As I say, they have had other failures to launch over the last decade. This is not a three-word slogan. It is just too complicated to be executed properly.

These things do not have to be made as hard as they look. I strongly believe that people will support the use of data to improve our health, but they want to know that it will not be flogged off to a political donor for goodness’ knows what purpose, and that it will not be given to a company for nothing to help it develop treatments that then get sold back to us at a significant premium. I do not think the tests proposed are too much to ask. There is so much suspicion these days about the use of data. Conspiracy theories abound, and the loss of confidence will set us back for a significant period. That is why I find it so hard to understand why we are not taking the opportunity in part 2 to rectify the mistakes over the summer and the previous decade, but amendment 109 seeks to help.

The Committee took evidence about this matter from NHSX at the beginning of our second sitting, which already seems a long time ago, and Simon Madden, the director of data policy, stated:

“Above all else, I think that the overriding need for trust and transparency—to build public trust in the use of health data—is vitally important”.

That is bang on the nose. I did not hear the Minister say that in his opening speech, so I hope we will when he

responds. There needs to be an understanding that the failure to handle GDPR properly has really set us back.

What I could not understand, though, was the witness’s next answer, when I asked about the process enabled by part 2 of the Bill and the future resumption of GDPR, or presumably a successor programme, and whether they would run together. I felt the two answers were contradictory. The witness stated:

“Essentially, they are separate in terms of process”.

He then said:

“The general public will not make a distinction between any things to do with their health data.”—[*Official Report, Health and Care Public Bill Committee*, 7 September 2021; c. 37, Q46-7]

I would argue strongly that it is the second statement that is correct. Anything to do with data in part 2 of the Bill or a resumption of GDPR, or a successor to GDPR, will be considered the same thing by the public. It will be regarded with suspicion because of the mistakes that have been made. Amendment 109 seeks to pull the processes together into one place because, as the witness said, the public will think of them as one thing, and we ought to treat them as one thing.

Clause 80 enables a health or social care body to extract relevant data from another such body. I have no problem with that in an integrated system, but it cannot be decoupled from future attempts to create a single health and care information database, as the Government sought to do over the summer. I hope the Minister will say that the process in part 2 of the Bill and other processes that may return in future are two parts of the same whole and as such will be treated that way, or we will make the same errors. I desperately hope that we will hear that today. As I have said, clause 80 is important. Amendment 109 makes it better. I hope to at least hear from the Minister a desire to bring all data programmes under one roof. In principle, we need organisations to talk to each other, and there is a requirement for that to happen.

During party conference, I escaped briefly to meet people at the Macmillan Horizon Centre in Brighton, which supports people and their families living with cancer. I met a man called Marc Valentine who is living with cancer. Due to delays with his care, his cancer is now terminal. He visits multiple hospitals and care settings for guidance and treatment but, in an example of massive system failure, his records do not follow him from meeting to meeting. Here we have a person with cancer who had sat down with a world-class cancer clinician who said she could not offer guidance because she simply did not know anything about his case. As a system, we have wasted the one thing that Marc does not have—time. We can do much better.

The clause will help by allowing organisations to demand such information of each other. That is probably second-best; it would be better for information to be readily shareable. That is why Labour are proposing this amendment. We have heard that the public will not differentiate between the different processes, and I cannot quite understand why the Government propose to make them.

Dr Philippa Whitford (Central Ayrshire) (SNP): It is important that we recognise the different types of data. The clause is talking about anonymised data, from which we are looking at performance standards, outcome standards and the percentage of patients who had a

[*Dr Philippa Whitford*]

certain treatment. It is not talking specifically about identifiable data. We also have fully identifiable data with patient details, and in between those we have what is called pseudonymised data, which is like a blurry picture. However, the public are also concerned about that data because they fear that when it is triangulated with other sources somebody can be identified.

It is important that clinical data—the basis of communication between a GP, a breast surgeon like me and an oncologist in a centre—moves around and can be used. However, we must recognise that, as the hon. Member for Nottingham North clarified with the survey that he quoted, the public are concerned about their data. Beyond someone's biological self, the most important thing that relates to them is their personal data, and after the care.data scandal of seven years ago and Google DeepMind, the public do not trust programmes that suddenly appear with little discussion and consultation and that talk about taking data. There is a huge public education process to be carried out, but equally, in the end, confidence is undermined by the talk about sharing data, whether identifiable or pseudonymised, with commercial companies.

Anonymised data is not an issue. For example, of the patients who took a drug, 10% got a side effect and, of those, 3% had previous heart disease. That is useful information; it does not identify patients. The public's concern is that commercial companies, including pharmaceutical companies, could access pseudonymised or full data that would identify them. It is important that the Government explain the three types of data and how they are used for utterly different things. The public have no issue with Public Health England or academics working to recognise what is happening with heart disease or cancer in the UK and learning from data. However, they are concerned about the potential commercial use and potential revelation of their personal data.

The Government have a long job to do to convince the public. The danger is that the baby goes out with the bathwater and we lose not just research but integrated functioning in NHS England. It is important to recognise that the data held in the devolved health services is completely separate. I will come to that on clause 85.

Karin Smyth (Bristol South) (Lab): Unfortunately, Mr Bone, you missed our last sitting, in which I relayed to other Members my long career in the NHS and my experience on these matters, but I will start in the spirit in which I left off. Having worked at a clinical commissioning group at the time of the care.data episode, I absolutely concur with the comments made by the Labour and SNP Front Benchers, my hon. Friend the Member for Nottingham North and the hon. Member for Central Ayrshire.

We have had a lost decade, which is a great shame because the use of such data—we have learned much more about data and science during the pandemic—can save lives. My hon. Friend the Member for Nottingham North mentioned meeting a patient who could perhaps have been helped better. At the end of the day, that is what we want to make happen.

My experience inside the health service will not be everybody's, but on information governance the attitude to data is very well developed and sophisticated, and

people take it incredibly seriously. When we started on the care.data episode, the value of that really seemed self-evident in the system.

We need to bear in mind, as we look at the issue as legislators, that the people who deal with it day to day to effect what they see as positive change may be operating on one track and be completely taken by surprise by the public reaction. I remember trying to understand it myself; I am not a data specialist, but I tried to understand the different channels of what was being tried at the time. I explained to more senior managers that it did not sit right with me—I did not understand where it was going or what it meant for me. If I did not understand it, I knew that if it were not explained carefully, as the hon. Member for Central Ayrshire says, the general public would not either.

There is a missed opportunity. I ask the Minister to consider our very helpful Opposition amendment, not just in his role as a political leader in the Government, but by thinking about the rest of the system and how we can support it to do what it needs to. We absolutely need to bring the general public with us. Because of the mistakes of the past, I would argue that that we now require quite a mammoth exercise: not just differentiating between types of data, but considering who owns it, how we give it and what powers we will have in future.

As my hon. Friend the Member for Nottingham North said, the opt-out was really quite an incredible exercise over the summer. I think that has gone below the political radar in terms of the numbers of people who have taken that really quite difficult step. Part of this, as we will come to later, is about trust in GPs and GP data, which is where so much of our individual source data goes. The role of GPs also has to be brought very carefully along the path, because that data is of course very valuable for them.

The commercialisation concerns people, but beyond that, this is about our very essence—our trust in the system and the clinicians we see, who most of the time are our GPs. The Government need to step back—although not for too long, because they have already stepped back for a decade—and consider what is the best public exercise that they could embark on to resolve this problem, as the system and all of us really need.

Accepting our amendment in the spirit in which it was moved would be a step in the right direction. If the Government do not accept it, at the very least we should understand what they propose in its place.

Edward Argar: I am grateful to the hon. Member for Nottingham North for tabling amendment 109. I appreciate where he is coming from; as I understand it, his amendment is intended to ensure that the clause does not require health and care organisations to provide information that they could already be required to provide under existing powers. He talked about consistency and a single approach, and he is right.

The hon. Member for Bristol South is absolutely right, as is the SNP spokesperson, the hon. Member for Central Ayrshire, about the need for us—the Government, the system and indeed all of us—to better explain and reassure people about the fact that data saves lives and about how it is used. The hon. Member for Central Ayrshire was right to draw a distinction between pseudonymised and anonymised data. She was equally

right to highlight that pseudonymised data is not relevant under the power, which is about anonymised data. In a sense, the reassurance is there, but it is incumbent on us to make it clear to people.

10 am

We have seen in individuals' treatment and care pathways the value of data shared and the benefits that it can bring, but we have also seen that more broadly in the development of new drugs and treatments and the benefits that can come from science and research. It is a challenge on occasion to draw a neat line, because some commercial entities develop drugs and do the research. The hon. Member for Bristol South made a key point. She will correct me if I have misunderstood, but people's concern is not about anonymised data being used to develop drugs that will save lives; it is about where there is a commercial impetus behind it and a commercial gain, and whether the data could be used in a particular way.

In terms of safeguards to prevent private companies from requesting data and using it for commercial purposes, the power to require the anonymous information applies only to public bodies. All NHS organisations will be expected to meet very high standards around the transparency and accountability set out in our five principles governing data-sharing arrangements entered into by NHS organisations, published in July 2019. Those include the principle that any use of NHS data not in the public domain must have an explicit aim to improve the health, welfare and care of patients in the NHS, or how it operates, and relevant bodies would have to continue to comply with those standards.

The hon. Member for Nottingham North made a point about different strands and paths being applied to different things. In June 2021, the then Secretary of State published "Data saves lives: reshaping health and social care with data", which is the overarching strategic approach. In reality, a lot of what is in that does not require legislation. We do not want to over-legislate, but we are seeking to fill some gaps.

On the hon. Gentleman's underlying points, the clause his amendment seeks to tweak is designed to enable individual health and adult social care public bodies to access anonymous data to support their functions. It is clearly intended to establish that sharing anonymous data to help staff do their jobs is a key duty and responsibility of all organisations that provide health and social care services in England. It applies only to information that does not relate to identified or identifiable individuals. The information can already be shared without the need for further safeguards around privacy and confidentiality. The Bill does not provide an alternative route for sharing personal or patient information that would be subject to safeguards and data protection legislation, or make any other provisions applying to data-sharing programmes, such as the General Practice Data for Planning and Research programme.

The June strategy that I referred to includes a commitment to reduce the data burden for health and care staff. That is why the clause does not expressly require organisations to process information to render it anonymous so as to comply with a request. We have also taken regulation-making powers to enable exceptions to the power to be made. Again, we come back to seeking to provide appropriate safeguards, but minimising the burden.

The hon. Member for Nottingham North touched on regulations. Key to our consideration of what exceptions should be included in the regulations will be minimising that burden. That could include providing that the power does not apply to information available through other means, and we do not intend to commence the clause until the underpinning regulations are also in place.

On the hon. Gentleman's amendment, I entirely understand where he is coming from, but I fear that it is not necessary for safeguarding patient information, given that the clause relates only to anonymised data and not to identified or identifiable individuals. I fear equally that it would not go with the grain of seeking to ensure that the burden of data sharing is minimised. In particular, it would appear—he may correct me on this—to require the Secretary of State to carry out a review before each request is made under the clause and to lay a report before Parliament.

I ask the hon. Gentleman not to press the amendment to a vote, although I suspect he will. I am happy to have further conversations with him about what he seeks to achieve. Hopefully, I can give him more reassurance or, if I cannot, explore whether there is more that we need to do in this space to reassure him, the Committee, the House and the broader public on the points about confidence made by the hon. Members for Bristol South and for Central Ayrshire. On that basis, I gently encourage him to consider not pressing his amendment to a Division, and I am happy to engage with him and the Committee if he feels that that would be constructive.

The Chair: Alex Norris, gently or otherwise.

Alex Norris: I thank colleagues for their contributions, which I thought were really good. This is an important area, and it is important that we give it a proper look. The points that the hon. Member for Central Ayrshire made about the different types of data were important, and the run-through of their benefits and disbenefits was well made. I know that we will get to them again when we debate future amendments, so I will not prejudge that conversation. I still feel strongly—this relates to what the Minister said—that we have reached a point in the public conversation where there is no differentiation left, and that is the point that Simon Madden made. Because the temperature of the discussion has been elevated, they will be seen as one. That is what I have sought to address in my amendment.

My hon. Friend the Member for Bristol South was right to say that we have had a lost decade. That is, sad because it means that there have been healthcare improvements that we have not made. Over that time, extraordinary workforce gaps have emerged, and we would perhaps have been able better to plan around them if we had had a greater sense of the growing healthcare needs in our population. She is right that getting public trust back will be a "mammoth exercise". That is why we have advocated for getting everything under one roof, in a single process.

The Minister mentioned that we all have a responsibility to explain data, and that it is important to make the arguments that we make in here out in our communities. I agree, but I feel I have much less of a responsibility to do that when the process is snuck out over the summer at short notice, without our ever having had a conversation about it. There could have been some effort to build consensus. I would have been willing to have difficult

[Alex Norris]

conversations with colleagues and constituents about it on that basis, but the way the process was handled made it impossible to defend. It left right hon. and hon. Members in the very strange circumstance of helping people to opt out of a system while thinking that that was not a good decision for them, or for anybody. As local representatives, we have a responsibility to people who ask for help.

I still do not get the sense from what has been said since then, publicly or in these proceedings, that the Government really understand the public message that they have sent, and I fear that that means we will keep repeating this conversation. In the amendment I simply ask that before the powers in the clause are turned on, a statement is made about how we seek to use these processes, and any other data processes, and handle them as one piece. That feels like a very modest ask.

I am going back and forth on whether to press the amendment to a Division. The Minister's offer was a kind one, and I am conscious that I am putting a lot of this at his door. He did not create this process, but he is here speaking to part 2, so it is at least half him. Perhaps, when the dust has settled from what happened over the summer, we can have a conversation soon between Government and Opposition Members about how to do such things differently in future.

Edward Argar: I am happy to reassure the hon. Gentleman that either I or the relevant portfolio-holding Minister will happily have that conversation with him.

Alex Norris: I am grateful for that, and on that basis I beg to ask leave to withdraw the amendment.

Amendment, by leave, withdrawn.

Amendment made: 121, in clause 80, page 71, line 20, leave out "250(7)" and insert "251C(6A)"—(*Edward Argar.*)
This amendment is consequential on Amendment 120.

Question proposed, That the clause, as amended, stand part of the Bill.

Edward Argar: As we alluded to in our discussion on amendment 109, the clause inserts a new section into the Health and Social Care Act 2012. It has the sole objective of increasing the sharing of anonymous data for the benefit of the health and adult social care sector. The provision applies only to information that is in a form that does not identify any individual or enable the identity of any individual to be ascertained. It allows health and social care public bodies to require such information from other health and social care public bodies and from others who are commissioned by public bodies to provide health and adult social care services. As we discussed in relation to amendment 109, the provision requires those bodies to share only information that they already hold in anonymous form; they are not required to process information held in order to render it anonymous.

The use of "anonymised" in the title of the inserted chapter is a typographical error to be corrected. It does not reflect a change in the policy intention, nor does it have any practical impact on the clause. Anonymous information—information that does not identify any individual or enable the identity of any individual to be ascertained—can already be shared without the need

for safeguards to ensure privacy and confidentiality. The provision will mean that public bodies will be able to require such information to be provided to them for the benefit of the health and adult social care sector.

The hon. Member for Nottingham North made an important point about understanding the message from the public on data. He may have a different interpretation, but I think the message was, "Data saves lives, but it is our data. We want to know and approve of how our data is used and have control over it." People recognise that data can improve care and treatment, but it is their data and they want to be reassured and comfortable about how it is used and the safeguards that are in place, and that it is their choice rather than something that is done to them.

The new power to require sharing of anonymous information will complement section 251B of the Health and Social Care Act 2012, which places a duty on certain health or social care organisations to share information about an individual with certain persons where that will facilitate the provision of care to the individual and it is in the individual's best interests. Both measures underline the importance of sharing data proportionately and appropriately to improve services and care.

The clause will also complement key provisions in the Bill, supporting those that strengthen the duty to co-operate across the health and care system. Regulations will provide for exceptions. Issues such as minimising the burden on providers and protecting commercially sensitive information may be taken into account when introducing exceptions. It is intended that proposed new section 251D(1), which allows for anonymous information to be required, will not be commenced until the regulations are made and the exceptions are clear. Given the extensive debate that we have had on amendment 109, I will stop there and commend the clause to the Committee.

Question put and agreed to.

Clause 80, as amended, ordered to stand part of the Bill.

Clause 81

GENERAL DUTIES OF THE HEALTH AND SOCIAL CARE INFORMATION CENTRE ETC

Question proposed, That the clause stand part of the Bill.

Edward Argar: The clause amends the Health and Social Care Act 2012 and requires NHS Digital, when exercising its functions, to have regard to the need to promote the effective and efficient planning, development and provision of health services and of adult social care in England. NHS Digital must have regard to that alongside various other duties, and the clause requires it to have regard to the need to balance those duties.

In addition, subsection (3) makes clear that NHS Digital may share information for purposes connected with the provision of healthcare or adult social care, or the promotion of health. That is intended to address previous confusion about when NHS Digital can share data by clarifying that it can share data for purposes such as planning the delivery of services and medical research. This will ensure that NHS Digital has the right powers and duties to collect, share and otherwise process data proportionately, appropriately and with due regard to protecting privacy.

10.15 am

The clause will also ensure that consideration of the benefits to the health and care system and the individuals served by it sits at the centre of NHS Digital's duties, alongside its other general duties. These include having regard to the need to promote the effective, efficient and economical use of resources, and to respect and promote the privacy of the recipients of health and adult social care, and a duty on NHS Digital to minimise the burden it imposes on others.

The clause acknowledges that NHS Digital's key functions may sometimes pull it in different directions, and that where that happens, it must balance competing priorities and outcomes—something we expect all organisations to do every day, but it should be explicitly acknowledged in NHS Digital's key functions.

We also want to provide greater clarity on the purposes for which NHS Digital can share data. It has a rich store of data, which, when used securely, safely and responsibly, can help ensure that everyone receives the best care and treatment—a point that the hon. Member for Nottingham North made in debate on the previous clause. The changes that we made to NHS Digital's legislative framework in the 2012 Act are intended to ensure that it can do that. The clause will not enable data to be sold to private organisations; I offer him that reassurance, as I suspect as he would have asked me for it in a moment, and I hope it is welcome to him. He may none the less ask me to reiterate that in my concluding remarks.

NHS Digital will continue to be subject to data privacy laws in relation to its use of data; also, its legislative framework and processes place strict controls on its dissemination of data. Those controls include a requirement that any sharing of information be for legitimate purposes, such as those connected with the provision of health or adult social care, and scrutiny by NHS Digital's independent group advising on the release of data, which advises NHS Digital on the appropriateness of sharing any confidential information. The clause will provide NHS Digital with the clarity it needs to use health and care data to benefit the public and support the health and care system safely and appropriately. I therefore commend it to the Committee.

Alex Norris: As the Minister says, the clause deals with the Health and Social Care Information Centre, known to its friends as NHS Digital. This is a crucial body, and everything we have heard in debate so far, and in part 1 of the Bill, makes NHS Digital's role even more central. The provisions in the Bill are modest; to use the Minister's preferred language, they are de minimis. NHS Digital will be crucial as the body that can bring together, under one roof, information held by various organisations, and that can make sense of multiple systems in order to get the right information out, which is difficult. As we have heard, the history is chequered.

I hope that when the Minister sums up, we will at least hear a commitment that goes beyond what is in the Bill, and that NHS Digital is empowered to get a grip on our data across the entire piece. This is very much in the spirit of what I just talked about; there are multiple processes, all of which will at some point go through NHS Digital, which makes it an important clearing house. I hope Ministers will have a keen eye on its resources, and technical expertise. There is a real need

for the organisation to demonstrate leadership, politically and at official level, and to pull the system together. I hope that we will hear a little about that, and about the outlook for NHS Digital. I am grateful for the point about private companies' data; I will not reiterate that.

Edward Argar: I am grateful to the shadow Minister for his remarks and their tone. I hope that I can reassure him, in the few brief moments that I will take to sum up, that we recognise entirely NHS Digital's current and potential role in helping to pull the piece together, adopting an holistic approach to data, and making sure that there is a coherent data strategy that works. I am confident and reassured that it has the technical expertise and resources to continue to develop its work and deliver for people in this country. I also reassure him that it continues to be a key priority of Ministers and the Secretary of State to ensure that NHS Digital has the tools it needs to do the job, so that, to go back to the thread that has run through our debate this morning, it uses its data to save more lives and provide more treatment, and does so in a way brings the public and our electors along with it. I hope that reassures him, and I am grateful for his remarks.

Question put and agreed to.

Clause 81 ordered to stand part of the Bill.

Clause 82

COLLECTION OF INFORMATION FROM PRIVATE HEALTH CARE PROVIDERS

Question proposed, That the clause stand part of the Bill.

Edward Argar: Clause 82 enables NHS Digital to require private healthcare providers to provide data, where this is necessary or expedient in order to comply with a direction by the Secretary of State to collect information. It does this by amending section 259 of the Health and Social Care Act 2012.

This provision will enable a consistent approach to the use of data, supporting improved safety and quality across private and NHS health services. The need for this was underlined by the Paterson inquiry, which examined the case of Mr Paterson, a breast surgeon who worked both privately and for the NHS and was found guilty of wounding with intent in relation to unnecessary surgery. NHS Digital has been working with the Private Healthcare Information Network to develop the acute data alignment programme. These provisions will support that work and enable data to be required from private providers where it is needed.

This provision is needed to ensure that the system has the information it needs to better understand the quality and safety of services across private healthcare and the NHS. NHS Digital will be able to exercise this power only where it has been directed to establish an information system by the Secretary of State, and information from private providers is necessary or expedient for that system to be established or to operate. That means we can ensure that demands on private providers are proportionate and necessary, and that they do not duplicate other requirements.

Clause 82 will provide NHS Digital with the powers it needs to contribute to the work that is being done to address issues of patient safety and quality identified through the shocking case of Ian Paterson. I therefore commend the clause to the Committee.

Alex Norris: We think that this measure is particularly important. Private companies must play their role in the process and share their information, just as we would expect the NHS and local authority bodies to do. However, we want clarity that there will be no refuge to be had from hiding behind bogus confidentiality on commercial grounds. That is not explicitly recognised in the Bill, but I am hoping that I have read this right and the Minister can confirm that that is because proposed new section 251ZA, which clause 79(3) will insert into to the 2012 Act, allows the Secretary of State to compel the provision of that information if they judge it to be necessary.

Edward Argar: That is my understanding. If I have misunderstood, I will, of course, correct the record for the shadow Minister.

Question put and agreed to.

Clause 82 ordered to stand part of the Bill.

Clause 83

COLLECTION OF INFORMATION ABOUT ADULT SOCIAL CARE

Alex Norris: I beg to move amendment 143, in clause 83, page 73, line 23, after “assistance” insert “or any form of reablement and rehabilitation provided under section 2 of the Care Act 2014 to reduce the need for care and support”.

This amendment is consequential on NC47.

The Chair: With this it will be convenient to discuss new clause 47—*Registration of tertiary prevention activities in respect of provision of social care*—

“(1) Section 9 of the Health and Social Care Act 2008 is amended in accordance with subsection (2).

(2) In subsection (3), at end insert ‘or any form of reablement and rehabilitation provided under section 2 of the Care Act 2014 to reduce the need for care and support.’”

This new clause would bring reablement and rehabilitation provided under section 2 of the Care Act 2014 to reduce the need for care and support into the purview of the Care Quality Commission.

Alex Norris: These measures would bring reablement and rehabilitation provided under section 2 of the Care Act 2014, for the purpose of reducing the need for care and support, into the purview of the Care Quality Commission. Unlike other adult social care functions, rehabilitation and reablement services are not currently part of regulated adult social care activities. There is no reporting, guidance on service standards, monitoring or inspection. That is despite the fact that rehab activities carry a level of risk similar to that of other adult social care interventions. This is particularly pertinent because rehabilitation services will be critical for those who are recovering from long covid.

One example that would fit into this category is vision rehabilitation. There is evidence from the Royal National Institute of Blind People that there are individuals who have been waiting since 2018 for their vision rehab. That will, of course, have been affected by the pandemic. However, those waiting more than two years, who have had this very profound change in their lives, need to develop new skills that they previously would have relied on their sight to achieve. The sooner that can be done, the better, because there are going to be so many other obstacles to adapt to.

The pandemic alone is not reason enough to offer comfort there. In the RNIB’s research, an inquiry made to lead councillors for adult social care in England last year found that about four in 10 did not know that vision rehabilitation formed part of that portfolio. An element of that will be because it is an unregulated function. Having been such a portfolio holder, I remember that you are very conscious of regulated provision in your area, because of the seriousness that comes with that, and I want to explore this gap a little.

Of course, the past 18 months have been extraordinary circumstances. Being a regulated activity on the same level of other adult social care activities would not fix the problems on its own, but it would have made a difference. It would certainly have given those gaps greater prominence. That might have been the beginning of addressing them. Indeed, there is a sense in the sector that this level of regulation would improve the visibility and priority of these services to senior managers and lead members by allowing for better data collection, for guidance, for quality standards to be developed by the National Institute for Health and Care Excellence, and for inspection services by the Care Quality Commission.

I will not say much more on that. It may well be that this is not the best mechanism to do those things, but I would be keen to understand why this particular element of adult social care is unregulated when so much effort is put into regulating other elements of it. Rehabilitation and reablement are particularly important.

Edward Argar: I am grateful to the shadow Minister for tabling the amendment and enabling us to have this discussion and air this issue. I understand his intentions in the amendment and new clause 47. It is right that social care services are appropriately and effectively regulated, and this includes rehabilitation and reablement. However, I do not believe that the amendment and the new clause are the right way of achieving the intended outcome.

Where providers carry out regulated activities as defined under schedule 1 to the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, rehabilitation and reablement services are already within the scope of the CQC’s activities. As such, most rehabilitation and reablement services are CQC registered and are usually carrying on the regulated activities of accommodation, personal care, and treatment of disease, disorder or injury.

The definition of social care in section 9 of the 2008 Act is already sufficiently broad to cover reablement and rehabilitation provided under section 2 of the Care Act 2014. If there are concerns about the scope of CQC regulatory activities in relation to these services, they would perhaps be more appropriately picked up as part of the ongoing review of the 2014 Regulations. That work would probably sit better there. We intend to publish the response to that public consultation on the review in due course. For that reason, I would encourage the hon. Gentleman to withdraw the amendment and perhaps seek to use that process and that review as the mechanism by which to further air these issues.

Alex Norris: I am grateful for that reassurance. That does provide comfort, certainly on the CQC aspect. The driver behind the amendment was as much that the CQC sharpens its focus for local authorities. I am not quite sure that we have got to the point where this will

close that gap. However, there is a good mechanism by which to do so, so I might pursue this later, rather than pushing it to a Division.

Amendment, by leave, withdrawn.

Question proposed, That the clause stand part of the Bill.

Edward Argar: This clause inserts a new chapter 3 into the Health and Social Care Act 2012, relating to information about adult social care. It introduces a new power for the Secretary of State to require regulated adult social care providers to provide information relating to themselves, their activities or individuals they have provided care to. The information may be sought only for purposes connected with the health or adult social care system in England, and its processing will need to comply with the UK general data protection regulation. Disclosure of commercially sensitive information is restricted under new section 277B(2).

As the shadow Minister set out, the clause enables the Secretary of State to delegate this function to the Health and Social Care Information Centre—known to its friends as NHS Digital—or to a special health authority, or to arrange for other persons to exercise them. Any such person would be subject to the restrictions on onward disclosure set out in new section 277B in the same way as the Secretary of State.

The clause is crucial for helping us to fill data gaps, understand more about self-funders and better manage emergency situations. Data from local authorities can show only part of the picture, as individuals who privately fund care have little or no contact with a local authority. That needs to be addressed to support local authorities to manage provider markets and secure improved outcomes for all receiving care and support.

The provisions will support a consistent and transparent approach to the processing of data across privately and publicly funded care to enable improved safety and quality of provision. Without that data, our ability to effectively identify and manage emerging risks and issues and to take appropriate action will be restricted.

The clause will enable us to collect higher-quality and more timely information, fill data gaps, support high-quality provision of services, and manage risks at local, regional and national levels. I therefore commend it to the Committee.

10.30 am

Alex Norris: To date we have discussed 83 clauses, and we might finally have found a little note of integration. Local authorities not only want to share their data, but they want a greater sense of the data that they do not have, as the Minister said. They are desperate to do this. They want the all the needs of their service users to be met, but they are frustrated by a system that is atomised and hard to navigate. We know that that is also exhausting for patients and their families. I know that local authorities will jump at the chance to use the provisions effectively, but I have a couple of questions.

First, is there an expectation and obligation that the data sharing will be a two-way street? There are times when local authorities are frustrated about their ability to get information either out from the centre or from local health services. I would not want that opportunity to be missed. Secondly, to reiterate a point I made earlier, it is a pain getting systems to talk to each other. Will the Minister and his officials look at what support and time may be needed to implement the measures?

Edward Argar: I am, as ever, grateful to the shadow Minister. On his final question, about the burden of the additional data that we want to collect, which is a fair one, the aim is to reach a point where we can collect and share data across the sector in a way that minimises those collection burdens. That will include giving careful consideration to the frequency and nature of data collection. We will seek feedback from those engaged in the process and carry out appropriate assessments of it.

The capacity tracker, which is a web-based digital insight tool that we used to collect provider data in near-real time to help manage the pandemic, currently has a very high completion rate. We do not anticipate that any further mandated collection will create a significant burden in addition to that tracker. We learned during the pandemic that it is one of the things that will have beneficial applications in future. The capacity tracker currently operates on a voluntary basis, but it has high sectoral coverage—about 95% of adult social care providers are voluntarily using it. That, I suspect, is motivated by the infection control fund incentives, but our intention is to make it as simple and as easy as possible for people to continue using the tracker without imposing a burden on them. We recognise, however, that if those incentives are not there, the balance of burden and compliance changes, so we are looking at longer-term collections, which would likely be required far less frequently than the frequent iterations involved in managing a pandemic.

We therefore believe that we have struck the right balance, but I assure the hon. Gentleman that we will continue to keep the matter under review and seek to strike the appropriate balance.

Question put and agreed to.

Clause 83 ordered to stand part of the Bill.

Clause 84

ENFORCEMENT OF DUTIES AGAINST PRIVATE PROVIDERS

Question proposed, That the clause stand part of the Bill.

Edward Argar: The clause inserts a new chapter into the Health and Social Care Act 2012 dealing with the enforcement of information provisions. It enables regulations to be made to impose financial penalties on private providers that, without reasonable excuse, fail to comply with an information standard or a requirement to provide information, or that provide false or misleading information. I am sure that you, Mr Bone, and members of the Committee will be pleased to hear that the regulations will be subject to the affirmative procedure in Parliament. This allows us to provide for enforcement in respect of private organisations, which are not subject to usual accountability mechanisms and judicial review in the same way as public bodies. The clause also provides for the regulations to set out details such as the amount of the penalty, as well as safeguards such as notice of the penalty and an opportunity for the person to make representations and to appeal to the first tier tribunal.

Clause 84 enables the Secretary of State to direct a special health authority to exercise the enforcement functions under regulations made under these new provisions and to give directions to the special health authority about the exercise of those functions. That provision and the related information provisions in the

[Edward Argar]

Bill are part of the wider strategy for health and care data, which aims to ensure more effective use of data across health and adult social care to deliver better treatment for patients, better health results for people who need care and support, and better decision making, research and support for those on the frontline. Our expectation is that those aims will be delivered through the commitments in that data strategy, including the legislative changes that we are making. The use of fines or, in the case of public bodies, judicial review is—as always—a mechanism of last resort but an important part of achieving those aims. I therefore commend the clause to the Committee.

Alex Norris: The clause is an important counterpart to clause 82. If private organisations do not comply with their duties, enforcement will be necessary, although we hope it will not prove to be so very often.

As the Minister said, much of this has been left to regulations, so we are flying a little blind, but his point about the affirmative procedure is welcome as we will have a chance to revisit the issue. Ahead of that, however, we suggest that the Government consider two things in formulating regulations. First, a private company should not be able to pay its way out of its responsibilities. The fine alone should not discharge the notice, and instead the information should still be forthcoming.

Secondly, in pursuit of that, under section 54 of the Modern Slavery Act 2015 the Secretary of State has the power to injunct a company and stop it trading if it does not comply with its responsibilities to publish a statement on modern slavery and its supply chain. A similar provision in the Bill would be highly effective. I hope that the Minister and his officials will consider that when they formulate the regulations. We will have a further debate on this at that juncture.

Edward Argar: I am happy to bear in mind those sensible points as we look to the formulation of regulations. I am grateful to the shadow Minister.

Question put and agreed to.

Clause 84 ordered to stand part of the Bill.

Clause 85

MEDICINE INFORMATION SYSTEMS

Dr Whitford: I beg to move amendment 65, page 77, line 3, at beginning insert “Subject to subsection (3A),”

This amendment, together with Amendment 66, would allow specified people and organisations who are required to provide information for a registry or information system to provide information to NHS Digital in pseudonymised form.

The Chair: With this, it will be convenient to discuss the following:

Amendment 66, page 77, line 12, at end insert—

“(3A) The provision mentioned in subsection (2)(b) must enable those required to provide information to provide information in pseudonymised form.”

See explanatory statement to Amendment 65.

Amendment 64, in clause 85, page 77, line 33, at end insert—

“(5A) The Scottish Ministers may exempt persons to whom subsection (5) applies and who are in Scotland from any requirements imposed by regulations under this section.”

This amendment would allow Scottish Ministers to exempt providers in Scotland from participating in any particular registry or medical devices information system.

Amendment 61, in clause 85, page 77, line 34, at beginning insert “Subject to subsection (6A),”

Amendment 62, in clause 85, page 77, line 47, at end insert—

“(6A) Provision under subsection (6)(c) and (d) may only provide for the disclosure, use or (as the case may be) further disclosure of information for purposes of public health analysis, and must prohibit disclosure, use or further disclosure of information for commercial use.”

This amendment would require that the disclosure of information will only be for the purposes of public health analysis and not for commercial use.

Amendment 63, in clause 85, page 78, line 1, leave out “includes power to vary or revoke the directions by a subsequent direction”

and insert “—

- (a) includes power to vary or revoke the directions by a subsequent direction, and
- (b) is subject to the consent of—
 - (i) the Scottish Ministers insofar as the direction makes provision for any matter which falls within the legislative competence of the Scottish Parliament,
 - (ii) the Welsh Ministers insofar as the direction makes provision for any matter which falls within the legislative competence of Senedd Cymru, and
 - (iii) the Northern Ireland Ministers insofar as the direction makes provision for any matter which falls within the legislative competence of the Northern Ireland Assembly.”

This amendment would require the appropriate authority to obtain the legislative consent of the devolved governments before powers under this clause are exercised.

Amendment 60, in clause 85, page 78, line 9, at end insert—

“(8A) Regulations under subsection (1) may not be made without the consent of the Scottish Ministers, the Welsh Ministers and the Northern Ireland Ministers.”

This amendment would require the Secretary of State for Health and Social Care to obtain the legislative consent of the devolved governments before powers in this clause are exercised.

Amendment 67, in clause 85, page 79, line 8, at end insert—

“(4) Provision under subsection (3) which changes the territorial extent of provisions of Chapter 2 of Part 9 of the Health and Social Care Act 2012 (constitution and functions etc of the Health and Social Care Information Centre) and—

- (a) relates to Scotland may only be made with the consent of the Scottish Ministers,
- (b) relates to Wales may only be made with the consent of the Welsh Ministers, and
- (c) relates to Northern Ireland may only be made with the consent of the Northern Ireland Ministers.”

This amendment would require the Secretary of State for Health and Social Care to obtain the legislative consent of the devolved governments before regulations under this provision are made.

Dr Whitford: I should like to speak to the whole group of amendments because they all relate to one another—amendments 65, 66 and 64 are very much about the form of data, which I discussed earlier.

The principle of the clause relates to the powers that are going to be given to the Health and Social Care Information Centre. It is given a power to require, so it can demand data. As a Scottish MP I am aware that data handling under NHS Scotland is different. Our data systems are different. We have a real concern that

there is no mention of consultation, let alone legislative consent. For the public across the UK, the way in which their data is handled, who owns and controls their data and what is done with it are critical. We did not take part in the care.data project or Google DeepMind. There has not been any attempt within NHS Scotland to commercialise data, but we have very innovative working from Public Health Scotland and the academic universities. We do not want to see that undermined.

It is disappointing that there is no recognition in the clause that there should be both consultation and consent from the devolved Health Ministers. Proposed new section 7A(2) and 7A(4) give the power to require, and amendments 61 and 62 relate to proposed new section 7A(6) on how data is used and to whom it is disclosed, which we discussed earlier.

On proposed new section 7A(3) relating to the form of data, I totally support registries, particularly of devices. We are all aware of vaginal meshes. I remember wading through case sheets at the time of the PIP breast implant scandal, even though I knew we had never used them, because the only way to prove that none of my patients had had them was to go through literally every single operation note and sign it off.

Amendments 65, 66 and 64 relate to the form of data and specify that the Health and Social Care Information Centre would have power to decide what kind of information would be included in individual patient information. Amendments 61 and 62 relate to what we talked about earlier: disclosure to third parties, which is of public concern.

Amendments 63, 60 and 67 relate to proposed new section 7B(5)(b), which is the power to change the territorial extent. Although most of these provisions talk about getting data on social care from local government in England, it is completely within this Bill that the information centre would be able to demand data from devolved health centres and that the Bill's territorial extent could be changed later by regulation, and without consultation, let alone legislative consent. All my amendments relate to the same basic principle: the four health services run separately, use different data systems and have different principles for sharing, using and analysing data, and whether they feel that sharing that with commercial companies is actually in the best interests of research, of patients and of clinical communication.

It is not necessary for pharmaceutical companies to have access to pseudonymised or individual data to study the functioning of their drugs. They require analysed, anonymised data that has been handled by trusted academics and researchers, whether from Public Health England or working in collaboration with universities. The amendments call for both consultation and legislative consent, without which the devolved health services and their principles of keeping data within the NHS and the public health system will be undermined. The Government need to talk to the devolved nations about that. They saw this Bill the day before it was launched. That is not consultation. That is not collaboration. That is not involvement.

It may well be that Ministers feel that a central registry of individual, identifiable details makes sense, or they may feel that it should be pseudonymised and brokered by the individual health services, because it will be those services that will have to contact patients if devices are found to be unsafe or need reviewing or if

people need further surgery. This is about the lack even of consultation. As we have talked about all morning, data is so important to the public and to patients that legislative consent should be put into all those clauses of the Bill. I am disappointed that none of the devolved Ministers got to see the Bill when it was being put together, and as we heard from the Welsh Health Minister during the evidence sessions, her concerns are exactly the same as those of the Scottish Cabinet Secretary for Health and Social Care.

That is what I call for the Government to do, and I look forward to the Minister's comments.

10.45 am

Alex Norris: I congratulate the hon. Member for Central Ayrshire on her amendments and the case she made for them. I remember with fondness that during proceedings on the Medicines and Medical Devices Act 2021 we were able to offer constructive ways in which information regarding medical devices could be collected and used. We managed to move the Government on that. I hope we have similar success on these proposals too, because those were arguments well made.

Amendments 65 and 66 get to the heart of building confidence regarding data among the general public. There is widespread understanding about anonymised data and about datasets so big that individuals cannot be recognised, but we know that sometimes, if we want more detail, and particularly around rarer conditions or in rural and more isolated communities, we risk identification. Giving our information leaders the tools with which to protect individuals while still delivering the desired outcome is a sound principle and is part of hearing the message that was sent from our constituents, so we can start to rebuild trust. Providing such extra tools would be proportionate.

Turning to amendment 64, devolution is at its best when the four nations can exercise the advantage of local knowledge and leadership but collectively harness separate oversight to tackle collective challenges. That is important, particularly for the use of data. I strongly believe it will be in the interests of people across the United Kingdom for all four nations to have similar systems of standards and alignment on data. I am conscious that the challenges in north Nottingham will be similar to the challenges in north Cardiff, but devolution may well mean that services in Cardiff are different from those in Nottingham; that is part of the process. It can also mean that the outcomes are different, and we may want to know that, so that one community can, if it wants to, change to replicate what another is doing. I am not arguing against common usage; I think it is important, but we do not want a situation where the Secretary of State seeks to act with overbearing control as a first among equals. The mutual benefits of sharing data are so clear to all parties that they ought to be able to be agreed on a good-faith and negotiated basis. It should not need compulsion from the Secretary of State; in fact, that would be a significant failure. Therefore, the opt-out specified would be proportionate in this case.

Amendments 61 and 62 are crucial. The general practice data for planning and research process fell over because a significant part of the population did not trust the Government to handle their data appropriately. There is widespread concern about the Government's relationship with big commercial entities, whether in

[Alex Norris]

the planning process, political donations or covid contracts. They are not scare stories or political fluff; they are real issues, they are in the public consciousness, and there is a sense that that relationship and the balance with the commercial sector is not one where the calibration is right.

On data, we must at every opportunity send the loudest possible signal that there are irremovable firewalls between people's data and commercial usage. That works on two levels. First, as mentioned there is a lack of trust that the data will not be handed over to big commercial companies. We know that the mega-giants in social media have an insatiable desire for our data, and the old adage that social media is only free because our data is the product rings true. The NHS is not like a social media platform, though; it is free at the point of use, but we have paid for it through our taxes. It is not a free service we get in return for sharing our data, and there is no mandate to simply pass on the information collected as a result of our healthcare.

Let us be honest: what confidence would we have in sending the Government to negotiate with these companies? We have seen the painstaking process involved in just getting them to pay tax in this country; I would not, with full confidence, send a Prime Minister to negotiate a fee for our data, because I suspect we would end up paying the companies. This is an opportunity to be absolutely, immovably and irreversibly clear that we do not think that they should be near this data.

Secondly, it is worth reiterating that it is not as simple as just not handing data over. Even through legitimate and beneficial use of data, we are still at risk of getting a bad deal. For example, we no doubt want to use population-level healthcare to work out what conditions we may need new treatments for in the future. For that reason, we want researchers to use this data, and from that new treatments and drugs will emerge. Big pharmaceutical companies stand to gain from this, so how is it to be accounted for? We have a stake and have played a part in that process, so we ought to have a share of the benefits. How will the premium that we pay for the new treatments reflect the contribution that we have made—bluntly, where is our dividend? Those are the reasons that the GDPR process fell apart, and why there is so much suspicion about the Government's handling of data more generally. If we keep repeating the same approaches we will get the same outcomes. This is a moment to change that and to send a signal that our data will be protected from commercial interests; I hope the Minister will meet this moment.

Finally, on amendments 60 to 63 and 67, I will not rehearse the arguments I have previously made. I can conceive of times when NHS bodies, local authorities, community and voluntary sector providers or private sector providers might fall short of the expectations we have of them on data sharing, and exceptions where the Secretary of State may need to step in. That is why the Opposition have supported earlier clauses in part 2. That is a reasonable and proportionate way of ensuring that the data sharing regime is an enabling regime. I cannot think that applies to the devolved nations. All four nations are partners in the common pursuit of improving health outcomes; we may diverge in approach, but the common goal is the same. I cannot conceive that

there will be such a divergence on data that it would be legitimate and wise to resolve it by working without shared consent. I hope, in the light of the arguments made, that the Minister will revisit that point.

Edward Argar: To the point made by the hon. Member for Central Ayrshire about the relationship with Edinburgh, while it is correct that a number of these clauses, and a large part of the Bill, were not finalised in their drafting until a day or two before publication, it is important to say that since the beginning of this year Scottish Government officials have had sight of the intentions and have been discussing with UK Government officials the wording and content of these clauses. I appreciate that this is not necessarily the same as a Minister seeing the exact wording, but that relationship and transparency has been there at that level.

I also put on record my gratitude to Humza Yousaf, the Cabinet Secretary for Health and Social Care. I spoke to him a week or two ago, and with tragic timing, in that conversation he asked me to pass on his best wishes to James Brokenshire for his recovery. I know that they got on well, and I hope that I have a similar relationship with Humza, who is pragmatic, and I appreciate the work that he is doing on this. We continue to talk, because I am keen that we have that healthy relationship and it is my intention that we respect the Sewel convention and work together to come to an agreed position. It is challenging because there are genuine differences of principle on how things should be interpreted, but I am committed to working with him, as he is with me, to find a way to reach a common position that respects everyone's principles and approach.

The medicine information systems clauses give us an important opportunity to ensure we have the highest quality evidence on which to base critical regulatory decisions. If we get this right, there is real potential, which has been alluded to by all Members, to take a step forward in the way medicines are monitored, risks are identified and action is taken to protect patients. We need to provide for the most effective operation of this system to realise the full benefits for patients across the UK.

The detailed operation of the system will need to be carefully considered further as we develop the regulations under the clause. It will probably be important that the systems are able to receive information that is fully identifiable to ensure accurate linkage and deduplication of data. That is necessary to ensure that the information system is able to capture a comprehensive picture of a patient's treatment to generate robust evidence, and that if a patient moves from one area of the UK to another, they are not lost from the registry.

Robust decision making on patient safety must be made using accurate data, which can only be achieved by processing identifiable data from the four nations to create the UK-wide information system. That necessitates precise data linkage due to the nature and potential rarity of harmful events based on multiple identifiable data points. It is proportionate to use identifiable data to understand potentially adverse patterns early.

Patient-identifiable information is also necessary where inclusion in a registry is to be used as a risk minimisation tool, where a patient needs to be identifiable in the registry to their healthcare providers, or if information systems are linked with wider safety monitoring mechanisms

already in place, such as the yellow card scheme, through which the public and healthcare professionals can report adverse incidents experienced with a medicine to MHRA, to further strengthen the data it collates.

It is not necessary to make provision in the Bill, because the powers in clause 85 give the ability to follow the most appropriate approach on the collection and disclosure of data, following discussion with stakeholders on the detail of the future regulations. The confidentiality and security of patient data and the reassurance that offers to patients is paramount. I hope I can assure the hon. Member for Central Ayrshire and other Members that all data held in a medicines information system will be processed in compliance with data protection legislation, which places crucial safeguards on the use of that information. That includes data principles such as lawfulness, fairness and transparency, purpose limitation and data minimisation—meaning that the minimum necessary information will be collected to meet the required purpose.

I recognise the importance of ensuring the appropriate and proportionate use and access to information in a medicine information system. As part of our consultation on the regulations to establish and operate a medicine information system, we will engage with patient groups and other stakeholders across the UK, as well as the devolved Administrations, on the content and scope of the system to ensure we do what is right for patients.

On amendment 64, at official level we have been in discussions with the devolved Administrations since February about the provisions in the Bill, particularly those for which at an early stage we identified a shared agreement that legislative consent was required. Clause 85 is one of those. I would like to put on record my gratitude to those officials—we often talk at ministerial level, but they worked very hard for some time in the spirit of finding a way forward that works for everyone. Let me say the same in respect of the devolved Administrations, who have spent considerable time working with us.

Without going into too many details, because those discussions are continuing, I have had constructive discussions with the Cabinet Secretary for Health and Social Care in Edinburgh. I am keen, as he is, to do what we can to move those discussions forward. I hope we will be able to provide further reassurance over any outstanding areas of concern to the DAs, and where necessary and agreed, to table amendments ahead of Report. I hope that gives the hon. Lady some reassurance that I am directly engaged with the Cabinet Secretary and I will continue to be so. I am due to have another conversation with him in the coming days, and I have in my bundle another draft letter I am due to send him addressing some of the details of the granular points we are now looking at. I hope we will be able to make progress.

For medicine information systems to be truly effective as a tool, they need to cover all patients using the medicine across the UK. The regulatory decisions taken on the basis of the data collected will apply to the licensing of that medicine across the whole of the UK. My concern about Scottish Ministers choosing whether Scottish providers should or should not participate in the information system is that it could risk a fragmented approach, which is why we are having those discussions at policy level.

11 am

The amendment would apply only to medicine information systems. However, I note that the hon. Lady also refers to the medical devices information system. My memory may fail me, but I recall that the regulation enabling the medical devices information system was introduced in the Medicines and Medical Devices Act 2021, which was passed by both Houses and was subject to a legislative consent motion, agreed by the Scottish Parliament at the time.

The amendments in the Bill related to the medical device information system are technical in nature. We believe that, having got where we are, it would not be appropriate to revisit those substantive points, which were debated fully and voted on in the context of that previous piece of legislation. I again commit to working as closely as I can with the devolved Administrations to find a way forward.

Turning to amendments 61 and 62, as we have debated in other clauses, the Government are committed to championing the safe, effective use of data, enabling it to flow in a lawful, secure and appropriate way to improve outcomes for citizens. NHS Digital allows information to be used for purposes connected to health and care by organisations that have a legal basis and legitimate need to use the data. That approach enables data to be made available for a range of purposes that improve health and care. In some instances, such a use may have a commercial aspect, for example when informing the commissioning of tertiary services, such as paediatric services for children adversely affected by medicines taken in pregnancy, or when supporting research by organisations at the earlier stages of developing new treatments.

I recognise that individuals, regardless of where they live in the UK, will rightly want to be reassured that their information will be used in a trustworthy and appropriate manner. NHS Digital does not approve requests for data where the purpose is for marketing, insurance or similar purposes. That would extend to systems established under this clause. We would also continue to build on the safeguards in place to ensure that information will be appropriately protected and to ensure transparency about how it is used and by whom. The Government will work closely with the devolved Administrations to ensure that differences in approach to the use and disclosure of information across the UK are taken into consideration in developing the medicines information system.

Finally, I turn to amendments 63, 60 and 67. Amendment 60 would require consent to be obtained from all the devolved Administration Ministers in each case where the regulation-making power in clause 85 relating to medicines and information systems is exercised. Similarly, amendment 63 would require consent to be obtained from the devolved Administrations before the power in clause 85 to give a direction can be used. Amendment 67 would require consent to be obtained from the devolved Ministers before the power in clause 85(5) relating to territorial extent of the Health and Social Care Act 2012 could be exercised.

Clause 85 would enable the capture of data on the use of specific medicines throughout the UK to support high-quality evidence on their use, benefits and risks, and will be a significant step forward in improving the monitoring of medicines. As I have said, we are seeking

to implement a system that works for the whole of the UK and ensures the safety of all patients. I reiterate that I am committed to working with the devolved Administrations to see if we can do just that.

The crux of what the hon. Member for Central Ayrshire is getting at is “consult or consent”, and the difference of interpretation on which is the more appropriate. Without going into too much detail, those are exactly the conversations I am having with her colleague, the Cabinet Secretary for Health and Social Care. Those discussions are ongoing, but I hope we will be able to make further progress. My previous conversations with him have been typically well informed and positive, and I hope we continue to make further progress.

It is important to be clear that clause 85(5), which would be affected by amendment 67, is a technical provision. Regulations made in relation to medicines and medical device information systems will introduce more substantial functions for NHS Digital in relation to Scotland, Wales and Northern Ireland. To ensure that NHS Digital can effectively undertake its UK-wide function in relation to the medicines and medical devices information systems, it is appropriate that certain provisions relating to the Health and Social Care Act 2012 can form part of the law for the whole of the UK. That is achieved through the power in clause 85(5).

That power can be exercised only as part of the regulations that deliver either the medicines or the medical devices information systems. The power applies only to certain provisions in the Health and Social Care Act 2012 that relate to the functions and constitution of NHS Digital. Therefore, use of the power is appropriately limited, and is also subject to the same public consultation requirement before any changes can be introduced through those regulations. It is not the intent to impact the range of other elements of the 2012 Act outside of the context of NHS Digital’s functions under the Medicines and Medical Devices Act 2021.

The Government are committed to ensuring that all patient data are captured efficiently, stored safely and used effectively, including those from patients within the devolved Administrations. To reiterate one more time, I commit to continuing to work closely with the devolved Administrations in discussions on this. I cannot promise what the outcome of those discussions will be; that would be wrong while they are going on. However, I commit to continuing to engage in good faith with the devolved Administrations to see whether we can make further progress. On that basis, I hope that the hon. Member for Central Ayrshire might consider withdrawing her amendment, but obviously that is her choice.

Dr Whitford: I welcome the Minister’s constructive comments. Obviously, I am not party to the consultations that are going on. I am still disappointed that there was not provision for both consultation and, where necessary, legislative consent. As the Minister clarified, those registries will absolutely contain individual patient data. As a surgeon, of course I support the principle of registries and how they are put together, but the responsibility for data in NHS Scotland and in the other devolved nations lies with the Health Ministers of those nations. It is disappointing that there was nothing put in these provisions.

I hope that the consultation goes forward. I will therefore not push the amendments. Obviously, I reserve the right to table amendments at a later stage. However,

it is important that the Government recognise that the same concerns that we have heard around GP data in England would then apply in Scotland, where we have not taken any kind of commercial approach in the past, and that there will be a recognition of the role of those health Ministers. I beg to ask leave to withdraw the amendment.

Amendment, by leave, withdrawn.

Question proposed, That the clause stand part of the Bill.

Edward Argar: As we have discussed in the context of the various amendments, clause 85 inserts a new chapter, 1A, into the Medicines and Medical Devices Act 2021. It introduces a new power to make regulations that would provide for one or more medicines information systems to be established and operated by NHS Digital. The power may be exercised only for the specified purposes set out in the provision: namely, purposes relating to the safety, quality and efficacy of human medicines and the improvement of clinical decision making in relation to human medicines. The clause sets out the types of provisions that could be made by the regulations and, to ensure full engagement, includes a mandatory public consultation requirement that must be fulfilled before any regulations are made.

Medicines information systems will enhance the capture and collation of information on the uses and effects of specific medicines across all four nations, including medicines prescribed to patients by the NHS and private healthcare providers. That information will be used by the Medicines and Healthcare Products Regulatory Agency to enhance post-market surveillance of medicines by enabling the development of comprehensive UK-wide medicines registries, which will be used to drive improvements to patient safety. The evidence generated through medicines registries can be used to inform regulatory decision making, support local clinical practice and provide prescribers with the evidence needed to make better-informed decisions. For example, where safety concerns have led to the introduction of measures to minimise risk to patients, comprehensive medicines registries will enable early identification and investigation of cases where those measures are not being followed, so that additional action can be taken to improve safety at national, local or individual patient level.

The clause also ensures that we have the right powers to promptly modify what data is collected by NHS Digital as the need for new or different information about a medicine emerges in the light of changing or developing public health needs. That will provide the ability to rapidly respond to emerging risks to patient safety if and when they develop.

Given the overarching aims of the clause, it makes sense that the provisions will ultimately sit within the Medicines and Medical Devices Act 2021, which has a similar power for establishing information systems for medical devices in section 19. To ensure the effective operation of both the medicines information systems and the medical devices information systems, the clause also introduces necessary technical amendments to the MMD Act.

The clause drives forward improvements to the safety measures that protect patients in the UK against avoidable harm from medicines, and supports the need for the establishment of registries as recommended in the

independent medicines and medical devices safety review, published last year. The clause directly supports putting patient safety at the heart of regulatory decision making. It will ensure that we have robust and comprehensive evidence to address public health concerns, and enable mechanisms to track the use and effects of medicines, based on public health needs. I therefore commend the clause to the Committee.

Alex Norris: I had intended to go the entire period that I am in this place, however long that might be, at least trying to be a young Member, if not a new Member, but clause 85 amends a piece of legislation that I was on the Bill Committee for previously, so I feel that I cannot do that now. That is really startling. Nevertheless, as I said earlier, I and the hon. Member for Central Ayrshire argued strongly for this in Committee on that Bill, and I certainly would want to see this used properly and developed. With all the daily treatments that there are—and certainly when it comes to the medical devices that are inserted into people on any given day and on every day of the year every year—we really ought to know what those things are and, when there is a problem, be able to deal with it quite quickly.

I will make one final point. The Minister references, quite rightly, the independent review—the Cumberlege review. We will be revisiting the matter in the new clauses, because the Government have not done the job properly on that review. Although there are elements in this clause that make good on some of the commitments, there are very significant things that have been left out and that the Government do not intend to do, and they have really let down the families by not doing them, so we will be returning to that point, and I hope to find the Government in listening mode when we do.

Edward Argar: I have nothing further to add to what we have said, save that I am always in listening mode when the shadow Minister is making his points.

Question put and agreed to.

Clause 85 accordingly ordered to stand part of the Bill.

Ordered, That further consideration be now adjourned.
—(Steve Double.)

11.13 am

Adjourned till this day at Two o'clock.

