The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 22 September 2015

Session 4

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CONTENTS

HEALTH AND SPORT COMMITTEE
25th Meeting 2015, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Malcolm Chisholm (Edinburgh Northern and Leith) (Lab)
Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Professor Alison Britton (Law Society of Scotland)
Amy Dalrymple (Alzheimer Scotland)
Trisha Hatt (Macmillan Cancer Support)
Dr Robert Hendry (Medical Protection Society)
Christine Lang (Citizens Advice Scotland)
Maria McGill (Children's Hospice Association Scotland)
Richard Meade (Marie Curie)
Peter Walsh (Action against Medical Accidents)

CLERK TO THE COMMITTEE

Jane Williams

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 22 September 2015

[The Convener opened the meeting at 09:30]

Subordinate Legislation

The Convener (Duncan McNeil): Good morning and welcome to the Health and Sport Committee's 25th meeting in 2015. I ask everybody to switch off mobile phones, as they can often interfere with the sound system. We are using tablet devices to access our papers instead of hard copies.

We have apologies from Rhoda Grant, who cannot be with us. There is no substitute member.

Public Bodies (Joint Working) (Integration Joint Board Establishment) (Scotland) Amendment (No 2) Order 2015 (SSI 2015/266)

The Convener: The first item on the agenda is subordinate legislation. We have three negative instruments before us. No motion to annul has been lodged in relation to the first instrument, and the Delegated Powers and Law Reform Committee has made no comment on it. If members have no comments, does the committee agree to make no recommendation on the order?

Members *indicated agreement.*

Public Bodies (Joint Working) (Integration Joint Board Establishment) (Scotland) Amendment (No 3) Order 2015 (SSI 2015/321)

The Convener: No motion to annul has been lodged, and the Delegated Powers and Law Reform Committee has made no comment on the order. If members have no comments, does the committee agree to make no recommendation on the order?

Members *indicated agreement.*

Self-directed Support (Direct Payments) (Scotland) Amendment Regulations 2015 (SSI 2015/319)

The Convener: No motion to annul has been lodged and the Delegated Powers and Law Reform Committee has made no comment on the regulations. If members have no comments, does the committee agree to make no recommendation on the regulations?

Members *indicated agreement.*

Health (Tobacco, Nicotine etc and Care) (Scotland) Bill: Stage 1

09:33

The Convener: Agenda item 2 is our fourth evidence session on the Health (Tobacco, Nicotine etc and Care) (Scotland) Bill. We welcome Christine Lang, who is patient advice and support service national co-ordinator for Citizens Advice Scotland; Dr Robert Hendry, who is medical director at the Medical Protection Society; and Professor Alison Britton, who is convener of the health and medical law committee at the Law Society of Scotland. Peter Walsh, who is the chief executive of Action against Medical Accidents, has had some travel difficulties but we expect him to join us.

We do not expect any opening statements. In the interests of time, we will move straight to questions.

Mike MacKenzie (Highlands and Islands) (SNP): My question is addressed to Professor Britton. Although I support the sentiment behind the duty of candour, I am grateful to her for providing in written evidence an indication of some of the potential problems. I ask her to elaborate on or reiterate some of those problems.

Members will remember that, at a previous meeting, I mentioned the analogous situation of road accidents. The small print of a driver's insurance says that any driver who is caught up in a road accident should not admit liability. With that analogy in mind, I ask Professor Britton to comment on some of the potential pitfalls of the legislation.

Professor Alison Britton (Law Society of Scotland): I will try. It would be logical to start with a question about the necessity of the legislation and what legislation of this nature would bring to the situation that is not already there. Two things are already there: a long-standing professional, ethical duty to have a good dialogue with one's patients or those for whom one is caring; and the need to build a relationship of trust. Without good communication and dialogue and a relationship of trust, the professions of healthcare and social care do not operate. Therefore, as I said, my first question is, what does the legislation bring that is not already there?

My second observation, which I hope is helpful, is that, if the legislation comes into effect as proposed, it will bring with it a dilemma. It is aimed at organisations, but it is almost impossible for those organisations to discharge the obligations in the bill, or even to try to implement the processes in the bill, without involving individuals. The provision of healthcare is not undertaken by an organisation; it is undertaken by individuals. That raises a modern dilemma for any organisation. On one hand, you are trying to encourage employees to be compassionate, to engage with the individuals for whom they are caring and to be emotional with regard to their circumstances—that is one duty that I hope that any organisation would have. On the other hand, there is another obligation, which I think is a modern one, to discharge duties in terms of compliance. Compliance is concerned with process, procedures and the parameters under which the first range of duties have to operate. It can be very challenging to operate those two elements in tandem.

Dr Robert Hendry (Medical Protection Society): I entirely support what Professor Britton said. It is terribly important that I make clear at the outset the fact that, as an organisation that supports doctors, the MPS absolutely supports a culture of openness, transparency and honesty when things go wrong. Our concerns very much echo Professor Britton's comments about whether the legislation will add to the culture of openness that, through educational processes, we are trying to support, or whether it will simply add a bureaucratic burden and become a box-ticking exercise that will have the opposite effect to the one that we want.

Mike MacKenzie: I take both those points, and I understand the suggestion that, as it stands, the bill might have a contrary effect. However, having listened to and carefully read the other evidence, I understand that there is a suggestion that the culture of openness and transparency is not as common as it ought to be. Can you suggest a way in which we can improve how that obvious problem is addressed that does not give rise to the legal concerns and pitfalls that you have helpfully pointed out?

Dr Hendry: That sounds like a question for me. When we survey our members, we find that there is still a culture of fear among staff in the health service at all grades. Despite the fact that we try to have a no-blame culture in the national health service in Scotland, that has not yet been achieved.

The way to achieve such a culture is through education. As the patient safety organisations, for example, have said, it is about changing the culture in the organisation, so that when something has gone wrong staff feel comfortable about coming forward and being absolutely honest and open about what happened, with the aim of learning from the incident and changing practice.

The imposition of more statutory duties, which people might not fully understand, becomes even more of an issue in the context of the proposals on wilful neglect. As Professor Britton pointed out, although the bill is designed to apply to bodies, it will be for individuals to ensure that they comply with its provisions. There is the potential for misunderstanding, particularly among more junior or less experienced staff, who might be anxious about breaching some of their statutory obligations—and that might add to the culture of fear and people's anxiety about being disciplined or subject to regulatory sanctions. Placing additional legal obligations on people who might not always fully understand them is not ideal.

We think that there should be support and education for staff, and parts of the bill go some way towards addressing the issue. If it is the Government's will to put in place a statutory obligation on candour, the important stuff will be the definitions—we can get into that in more detail, but the definitions are a bit loose at the moment and people might not understand what is required—and the training and support mechanisms that national health service organisations will be obliged to put in place.

Mike MacKenzie: I have a quick follow-up—

The Convener: Let us see whether the other witnesses want to respond. You need to give them time to do so.

Mike MacKenzie: That was exactly my point, convener.

Professor Britton: You asked about solutions. Let me make an additional point about education. I agree that we need to give people an opportunity to understand the implications of the bill, because it will not be effective if they do not do so. Our understanding of the bill and its impact is that it will change thresholds in relation to the definitions of harm and possible outcomes of harm. The bill changes or lowers some thresholds, and it will be important that everyone who is involved understands that.

At the other end of the spectrum, the wilful neglect provisions might criminalise behaviours that have occurred or which might have occurred—the near-miss scenario. If the bill is passed, it will be important to impart to the relevant organisations and individuals information about the changing thresholds, the extent of the thresholds and the possibility that some behaviours and near misses will be criminalised.

Mike MacKenzie: My concern is that it might take 10 or 20 years for the courts to deliberate on some of this stuff before there is clarity about what it means.

Professor Britton: I think that we will be looking at definitions. This is not the only bill in relation to which we can say that the better the definitions, the less we leave to satellite legislation and regulation or deliberation by the courts to interpret what is meant by a triggering event or an unintended or unexpected consequence.

Mike MacKenzie: Thank you.

The Convener: Dennis Robertson wants to come in. Is it a short supplementary question, Dennis?

09:45

Dennis Robertson (Aberdeenshire West) (SNP): Yes. My question is very short and it is to Dr Hendry, who talked about education and support. In some of the current codes of practice, there are no provisions about how often there should be supervision. Should we have mandatory supervision levels in codes of practice for nurses, doctors and everyone else—as there are in social care—rather than putting things in statute?

Dr Hendry: It is a good idea to clarify expectations in that regard. Concerns have been raised recently about levels of supervision of juniors in some health board areas. When things do not work out as well as we would want them to do, openness with patients works best in well-functioning, well-managed units, where there is a good culture. There is often more of a problem, and junior staff, in particular, fear that they will get into trouble, in units where there are poorer supervision levels and a poorer learning culture. I think that social work has been ahead of the health service in addressing some of those issues, so the point that you make is quite right.

The Convener: In our discussions with a practitioner yesterday, I think that I picked up that supervision responsibilities are mandatory in Northern Ireland. We can check whether that is the case.

Bob Doris (Glasgow) (SNP): Committee members met the Scottish Infected Blood Forum, Haemophilia Scotland and the Hepatitis C Trust in private last week to discuss the proposed duty of candour. The committee members who attended the meeting found the evidence helpful and powerful—I know that I did. There will not be a report of the meeting, but we hope that a short note will be produced that will set out some of the themes that were discussed and help us in our deliberations. I thank everyone who shared their stories with us.

Mike MacKenzie asked whether the duty of candour is needed, and I thought that in their responses the witnesses dealt with the issue fairly quickly, questioning the proposal without scrutinising it in great detail. Currently, health and social care professionals have an ethical requirement to disclose instances of harm, and last year healthcare professionals issued a joint statement about a duty of candour. I understand that candour is a requirement in the professional standards for doctors, nurses and perhaps other health workers.

Let us leave that to one side. Dr Hendry and Dennis Robertson suggested that social care is a bit further ahead on these issues, which left me thinking that there is perhaps a well-intentioned spaghetti approach in terms of what is regarded as an ethical or statutory duty of candour and when it should kick in. We have lots of examples of instances when candour is required, or would at least be best practice and ethical. However, I am confused as to whether we have an approach that is consistently applied across the health sector and the social care sector—and, indeed, as we move towards integrated health and social care and other services for older people, both sectors together.

There might already be best practice and various duties, but is there a consistent approach to what a duty of candour means and when it should be triggered? Is there an opportunity to bring some certainty to that for health and social care professionals?

Christine Lang (Citizens Advice Scotland): I know from our clients’ experience of making complaints to different health boards in Scotland that there are inconsistencies in the way in which health boards respond to those complaints. Some health boards are excellent at giving clients a full explanation of what has gone wrong, of the changes that they will make to make sure that it does not happen again and of the training that they will give to staff, if that is appropriate, but other health boards are much less good at doing that. Either they do not fully explain to the client what has happened or they are unable to give an apology, perhaps because of a fear of litigation. Our clients’ experience shows that there are great inconsistencies.

Professor Britton: This is a reflection more than anything else. I imagine that most people who work in the caring professions understand what “duty of candour” means: it encompasses the idea of dialogue, openness, trust and accountability, as we have discussed. However, consistency must be a very difficult thing to provide. Perhaps that is why, initially, professional organisations put forward practices and guidelines to enable consistency to be exercised within a profession. However, modern medicine and modern healthcare involve more of a multidisciplinary approach. For example, the treatment of an individual might involve nurses, community nurses, social workers and community workers. Because the duty of candour is quite an amorphous concept, it might mean different things to all of them, with the result that they will have different views on whether they have met it. Therefore, finding a consistent, one-size-fits-all approach is certainly going to be a challenge.

Dr Hendry: I agree with Christine Lang—there is undoubtedly variation from board to board, but we see variation in many other areas to do with health service management in Scotland. The issue comes down to what we said about the culture in a particular health board area or organisation, the quality of management—that is what allows things to be done—and, ultimately, the board's scrutiny of how patient complaints and concerns are dealt with. I am not sure that the bill would bring about more consistency, because that comes back to how any new statutory obligations would be monitored. I think that it has been suggested that Healthcare Improvement Scotland would do that. Would the bill assist HIS in bringing about a consistent improvement in performance across health board areas? The committee will have to ask HIS that.

Much of what we are talking about comes back to the quality of management and the culture that is set, which come from the top.

The Convener: Would it be useful at this point to reflect the concern that the consultant whom we met yesterday had about day-to-day clinical practice?

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): Those concerns could be raised, but I want to put a question to Peter Walsh from Action against Medical Accidents. There has been quite a lot of criticism of the duty of candour, but the submission from Action against Medical Accidents is a core document as far as the background to the issue is concerned. I wanted to ask about that, but perhaps the convener would like me to do that a little later.

One of the most interesting things that the clinician whom we met yesterday said—I am reporting her view rather than necessarily agreeing with it—was that some people do not want to be informed. Peter Walsh will want to respond to that when I question him later. That was the key thing that I remember from yesterday, although the convener's memory of what we were told might be more detailed than mine. The clinician in question was certainly strongly of the view that there were a large number of patients who would not want to be informed in the circumstances that we are talking about, although I wondered whether the situation might be different in the context of end-of-life care.

The Convener: I think that Bob Doris has a final question.

Bob Doris: I thank the witnesses for their answers. Maybe it is my fault that I am confused, so I apologise for my confusion. The replies that I got—with the exception of Ms Lang's, which I thought was quite clear—mentioned the need for greater consistency and questioned whether legislation actually adds to cultural change. However, my question was about clarity, rather than about consistency and cultural change.

The bill is fairly straightforward about what the opportunity is, what the guidance and guidelines will show and what training may flow from that, but I do not have any clarity, under all the different requirements that exist just now, about where the duty of candour kicks in. I am sorry if I give small examples of where that duty may never kick in, but I will use them for the sake of simplicity. Suppose that an elderly person in a care home or in a hospital ward has been assessed as needing two people for moving and handling, because of a continence issue or whatever, and that one of those people does not want to wait for a second person and thinks, "I'll have a go at that myself," and then there is a fall or significant incident. In such a case, the family might want some transparency and openness about the incident, but I do not know whether that would trigger a duty of candour requirement. The point that I am making is that that is a living, breathing example of the kind of incident that probably happens in our communities.

Similarly, drug errors happen in hospitals and nursing homes not through wilful neglect but because human error is part of being human. I want to know whether there is any guidance or clarity at the moment about what the requirements are when an error is made by nursing staff in administering a drug. I have given two examples of relatively low-level cases in which the high-end duty of candour might never kick in, but I am left with no clarity at all, irrespective of what the professional codes may say for doctors, nurses, care staff or allied health professionals, as to when the ethical requirement within those professional codes kicks in for real-life examples where a duty of candour, or of openness and transparency, should be employed. There may be significant issues about how to define the triggers; I understand that, but I want to ask about the opportunities that the bill provides to define better and to provide better clarity, because I do not see how we can get the cultural change or consistency that we need unless we decide what the baseline is from which to drive consistency.

I am sorry that I went on a bit, convener, but I think that that is important.

The Convener: That is fine. We are delighted to have Peter Walsh with us now; he has had transport problems. Do you want to come in with a bang, and answer that question?

Peter Walsh (Action against Medical Accidents): I would like to respond to those points. It is pretty clear that doctors and nurses have an ethical and professional duty to tell patients or their next of kin about any unintended or unexpected incident that has caused any level of harm. It is a more all-embracing duty than the statutory duty that we are talking about today, and it is basically what any of us would expect. Any decent health professional, if they know that something has happened that may have caused harm, let alone something that is known to have caused harm, would want to tell someone about it.

What is exciting and different about the statutory duty of candour is that it applies to organisations collectively and corporately, and it deals with situations where things go wrong. As Bob Doris said, there will always be incidents that should have been avoided and that are unexpected and unintended.

What also goes on, and has gone on for the whole history of the NHS and beyond, is an occasional lack of honesty. At the worst extreme, there have been quite deliberate and callous cover-ups: anyone who works in the health service or in social care will tell you that it happens. People have talked about the culture of the health service in the past. The culture of the system has been one that has, in effect, frowned upon any lack of honesty and openness, but has tolerated it.

I think that the bill is the final piece of legislation that will complete the Scottish approach to patient safety by filling in a missing segment. It says unequivocally that a lack of openness and honesty when harm has been caused, or is suspected to have been caused, is not tolerable.

There are definitions. I would like to summarise them as “any significant harm”—and not only harm that is known to have occurred, but potential or suspected harm.

10:00

The point about some people not wanting to know that a mistake has been made is a valid one. One must respect each individual’s wishes. When the discussions took place in England about its version of the duty of candour, we made that very point. The way that it has been dealt with in England is that there is a requirement to tell the patient or service user or their family that there is something to report and to discuss, and they can simply say, “Thanks, but I don’t want to know.” Let us say that mum or dad has passed away: the family can say, “We’re moving on and we don’t want to know another thing.” That is their absolute right, but it is not the right of any individual health professional or organisation to decide for them that they do not need the opportunity to know.

The Convener: There are no other responses on that, so we will move on to a question from Malcolm Chisholm.

Malcolm Chisholm: That was helpful—thank you. I was interested in the submission from Action against Medical Accidents because it gives some background. We are aware that a duty of candour has been legislated for in England—we see, behind that, the Mid Staffs inquiry——and you say in your submission, Mr Walsh, that you have been campaigning for such a duty for 20 years. I do not think that this has come from nowhere. There is nothing wrong with Scotland copying things from England if we think that they are good policies, but the Scottish version will be different in some ways.

The other interesting thing about your submission is that you are, in a way, suggesting amendments to the proposal here. For example, you are concerned about enforcement. In England, the Care Quality Commission has powers to ensure that the duty of candour is enforced, but it is perhaps not so clear what will happen in Scotland in that respect.

I would be interested to hear a little about the background. There are a couple of areas in which you would like the detail of the proposal to be changed. I am sure that others will want to give a different perspective, but it would be good to hear from Peter Walsh because the discussion before he came in was dominated by criticism of what is proposed. It would be useful to get a balance against that.

Peter Walsh: Certainly. On the background, it is perhaps an opportune time to pay tribute to the family of Robbie Powell. You might be aware that, in our original campaign for a duty of candour, we used the title “Robbie’s law” because of the death of a 10-year-old in south Wales and the heroic efforts of the family to get openness and transparency. There was an alleged cover-up in Robbie’s case. There was negligent treatment, but the reason why the case is significant for today’s discussion is the alleged cover-up and the fact that the case established that there was no statutory or legal obligation to be open and honest when things go wrong. As I said, the system frowns on cover-ups—of course, nobody would approve of that kind of behaviour—but it has been tolerated for decades.

People have also resisted for decades the notion of a statutory duty, and have argued that it would somehow have the opposite of the desired effect and would get in the way of an open and fair culture. There was a lot of resistance in England before the Government at Westminster eventually accepted the pressing need for the duty after the Mid Staffordshire inquiry, which looked at the arguments for and against in copious detail.

Since the policy was adopted in England, the people who were opponents of making the duty statutory and enforceable have moved on. It has been well received, on the whole, and people are getting on with putting things into practice. After all, if everyone preaches openness, honesty and doing the right thing, what possible problem could there be with putting that in statute?

Incidentally, no one has argued—certainly we have not argued—that passing legislation or regulations will change a culture. Legislation about discrimination on the grounds of race, creed or disability does not change the culture on its own, but underpins a change in culture that society demands. By passing the bill, the Scottish Parliament will send the clearest message that bad behaviour in terms of a lack of openness will no longer be tolerated, and that measures will be in place to ensure that the right things happen.

Of course, there will be a need for training, awareness raising and support for staff in doing the right thing. Far from having to copy England, Scotland has a great opportunity to get this right in a way that England has not yet entirely done. There are some mistakes or omissions in the original English approach that Scotland has the opportunity to sort out. Most fundamental is that it is possible to make sure that by the time the legislation comes in there is a co-ordinated, planned and resourced programme of awareness raising, training and support for the staff who will be responsible for implementing the policy. Sadly that is still not happening south of the border, but we hope that it will happen soon.

Enforcement is important. The public in Scotland will be saying that the bill is all very great, but it is motherhood and apple pie. Of course we expect openness and honesty, but what will actually happen when health boards or general practitioners do not comply with the duty of candour?

I had a helpful meeting at which Scottish Government officials explained the differences between the systems of regulation and monitoring and so on in Scotland and England and the rest of the UK, where we work. It might seem to be a throwaway line in the legislation about Scottish ministers having the ability to report, but the lay person would read it and say “Really? Is the consequence of failing to comply that you are named and shamed in the report?” Of course, that is not adequate. However, you will have the right situation if it is made clear to the public and service providers that such matters really are serious and that boards will have to sit up and take notice, otherwise serious consequences will follow, through ministers. Of course, we hope those measures never have to be used because the aim of the bill is to change culture and practice for the good, and the duty of candour underpins that. If the bill is to be meaningful, adverse consequences are an important ingredient, should people decide not to comply.

Professor Britton: I am still thinking about the deputy convener’s question about what consistency the bill will add. We have alluded to the position in England, but we simply do not know. Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, which deals with the duty of candour in England, has been so recently introduced that we just do not know. I understand that it has not been universally embraced and accepted. My reading of the evidence shows that there are still reservations and concerns, but given that the legislation has been passed, one would want to do one’s best. If you come back and ask the question in a year, we will have a much clearer idea of the position in England. As Peter Walsh correctly pointed out, the NHS in Scotland is a slightly different beast to what we are dealing with in England.

Also, we should not confine ourselves to the position in England; we should be looking internationally at what we can learn from our colleagues elsewhere. It is my belief that that has not yet been done. The concerns and issues around a duty of candour and how we interact with the people for whom we care must be universal considerations.

So, we are at this point: we have legislation in England, but we are not clear about its outcomes and consequences. Perhaps we should still be looking for evidence from elsewhere to get a clearer idea of whether, as Bob Doris said, it is possible to draft something that picks up the nuances of the diverse nature of our healthcare professions. It is for that very reason that policy, guidelines and regulations have evolved for health and social care that are bespoke to their own practices. Although the duty of candour is recognised, it is an amorphous concept.

Dr Hendry: I was interested in what Peter Walsh said, because he and I have talked before about the fact that there is some overlap. However, there are some concerns. Our experience in England, which Peter touched on, is that there is so far little evidence that education and support are being put in place. We have had feedback from general practitioners in England to the effect that they do not really understand what their duties are. They are anxious about the CQC—again, it is very different in England. There is a fear that they cannot discharge their duties properly. If the duty of candour provisions in the bill are to go ahead, I would underscore the importance of providing proper support and education around them.

Ultimately, what slightly concerns me is the idea that there will be tough enforcement—that something bad will happen to people if they fall foul of the legislation. It will be difficult to enforce and I would be concerned if the perception among the health and social care community was that this is yet another burden, and that something bad might happen to them, rather than the perception being that they are being encouraged to do exactly what we hope they would do.

At the end of the day, a scandal is a scandal. Would legislation really have stopped the problems at Mid Staffs or Morecambe Bay, or some of the other problems? Would it have just been yet another aspect to the scandal: not only had people breached common decency, let alone professional obligations, but they had breached the statutory duty as well? I am just anxious that the proposed solution would not have the intended effect.

Malcolm Chisholm: That was all extremely helpful. Can I bring in Christine Lang, who has extra suggestions? You are supportive of the duty of candour, but you feel that it is important that support be made available. It would be interesting to hear about that. You also made reference to the Scottish Public Services Ombudsman. I do not know whether what you said about that partly answers the question about what recourse people would have.

Christine Lang: If the duty of candour is introduced, we would certainly welcome people being directed towards independent advocacy and to the help that is available through the patient advice and support service that is delivered by citizens advice bureaux throughout the country. We would also welcome training around complaints and early resolution for NHS staff who deal with such things in hospitals and health centres. There is still a long way to go with that. As Peter Walsh said, if people are going to be asked whether they would like information, it is important that they are made aware that they can get support to help them through the process. It might be that someone could be made available to be with them when they are given news, or to support them through the process if they want to make a further complaint about it or to find out more.

The patient charter, which was introduced through the Patient Rights (Scotland) Act 2011, states that patients have a

“right to be informed, and involved in decisions”

about their care and treatment; to be treated with respect and dignity; and to have a say about their care. I do not know how they would have those rights if they are not given full information about what has happened to them or where things have gone wrong. We would certainly welcome that openness and honesty.

Malcolm Chisholm: Those were all my questions on the duty of candour. At some point it would be good to get comments on ill treatment and wilful neglect, but do you want to keep on the subject of the duty of candour at the moment, convener?

The Convener: I can bring you back in later or you can continue.

Malcolm Chisholm: Last week, most of the concerns that were expressed were about ill treatment and wilful neglect, whereas this week the balance of the evidence has been very much about the duty of candour. Some of you have covered it in your submissions, but it would be interesting to just open up that second big issue that we want to cover. Peter Walsh strongly supports what is proposed, but with some qualifications, on which he might want to comment. It would be useful to get your general views on that second area of potential controversy.

Peter Walsh: We think that in principle it has to be the right thing to have an offence of wilful neglect. We have all heard about some dreadful scandals and there is a public expectation that a strong line will be taken on such unacceptable levels of care.

10:15

Our concern simply lies around the legislation being directed very carefully. There is a danger of overdoing it and of punishing people who have been put in an impossible situation. That is our concern, although I understand that the policy intention is that the wilful neglect proposal will capture the management team that oversees very poor standards and will not be targeted at the front-line staff who may have been put in an impossible situation.

The Convener: How do we do that? How do we separate the individual from the organisation?

Peter Walsh: I have no particular expertise or wisdom to offer you on that. I just want to make a plea for fairness in how it is deployed. If the other things that we have been talking about around the duty of candour and other elements of patient safety are got right, we all hope that the offence of wilful neglect will never have to be used. That is the endgame. It is about having safeguards and about how the proposal is approached. It needs to be approached in a fair, sensible and proportionate way.

Dr Hendry: We have much more concern about the proposal that wilful neglect should be a criminal offence than we do about the duty of candour. With the duty of candour, we are all trying to get to the same place and the question is whether that approach is going to work.

We have serious concerns about the wilful neglect proposal. First, as drafted, it is focused on individuals. If we have a health service in which people are anxious because of the introduction of a statutory duty that might end up with someone going to prison, that will not foster a no-blame culture.

Secondly, the question is whether the proposal is necessary. Are we really saying that there are people at the moment who are getting away with those utterly unacceptable behaviours for want of a criminal sanction? It is absolutely unacceptable that people would either wilfully mistreat someone or wilfully neglect them. However, the criminal, disciplinary and other sanctions that are already in place are surely adequate to cover that.

The concern is that the proposal would fly in the face of what we are trying to achieve with the duty of candour provisions, which is to get people to be open and to be entirely transparent early on in a situation. If, sitting with that, we have the threat of criminal sanctions and imprisonment, that seems almost entirely counterproductive. I do not think that there are people getting away with such behaviours that we need to cover with new legislation on wilful neglect. Creating a climate of fear would run counter to what we are trying to achieve through any provisions on the duty of candour. We have fairly severe concerns about the wilful neglect suggestion.

Professor Britton: The Law Society did not make any submissions on the area of wilful neglect. The health and medical law committee focused on the duty of candour because we felt that it had a broader effect. The Law Society would be happy to consider the area of wilful neglect now that there has been further deliberation on it here.

I will make a personal observation, which perhaps takes us back to the point that Mr MacKenzie made at the beginning of the meeting. We have to be very clear in the terminology that we use. If we use the concept of wilful neglect, it has criminal implications and we should be very clear that we are not confusing it with a negligent act. Under current Scottish and English law, neglect or negligence in a healthcare setting is regarded as an unintentional act or omission. As soon as the word “wilful” is used, we have a criminal concept that means that an act was premeditated, intentional or exercised with such a degree of recklessness that it is considered to be within the criminal sphere. My personal observation is that what the bill proposes could mean somebody would be criminally investigated for a crime that might not have occurred, which takes us back to the idea of the near miss. The Law Society would be happy to develop further the concepts that we have discussed, if that would be helpful to the committee.

The Convener: It would be. Your general definition of a wilful act could be helpful for people working in the healthcare environment, because how a wilful act is defined is very important.

Professor Britton: I do not think that I am qualified to give such a definition for a healthcare context. However, a wilful act would normally mean a behaviour that was so reckless, intentional or premeditated that it could not be considered in any forum apart from the criminal law one.

The Convener: Colin Keir wants to come in. Do you want to ask a question about wilful neglect?

Colin Keir (Edinburgh Western) (SNP): No. I wanted to ask about the vicarious liability aspect of the issue and how that is addressed in other contexts, but I will come back to that later.

The Convener: I am quite happy to take members in turn from my list, but I will take anyone who wants to ask another question about wilful neglect.

Mike MacKenzie: Do any of the witnesses feel that, taken together, the offence of wilful neglect and the duty of candour could result in a kind of risk aversion? We have seen manifestations of risk aversion in, for example, the high-profile case of a lady—I think that she was a lawyer—who fell down a mineshaft; the fire brigade refused to rescue her because of health and safety concerns. We also hear about carers being unwilling to change light bulbs for elderly patients for the same reason. Is there a possibility that what is proposed in the bill will give rise to a risk aversion that could lead to a situation in which the cure is worse than the disease?

Dr Hendry: I think that you are right. It is difficult to predict how what is proposed would be interpreted by the healthcare and social care community. However, someone could go to their work and try to do the right thing but, because of unexpected circumstances, end up being in a police cell and being prosecuted. Perhaps the case would not proceed and they would not be taken to trial, but the fact is that they would have been involved with the criminal justice system. That would need to happen only once for it to have a devastating effect on the healthcare and social care community.

Apart from Shipman or somebody like that, it is very rare for somebody to set out genuinely to cause harm. Anybody who does so should absolutely be dealt with, but they can be dealt with adequately through the current criminal law. They would be suspended, sacked, prosecuted and all the rest of it. We are talking about cultural change, but something can be in people's minds because people sometimes get the wrong end of the stick or exaggerate concerns and so forth. If people who work in what can often be a highly stressed, underresourced and difficult environment have the thought hanging over them of, "If something goes wrong here, I might end up in jail," one would fear that they would either start to take inappropriate action or simply give up. At a time when we are struggling to attract people into the social care and medical sectors, making working in them even more scary could have a devastating effect on the professions, which would be completely out of proportion to any harm that people would be saved from.

Peter Walsh: I will concentrate on the duty of candour. The answer is that there is no danger of the effects that Mike MacKenzie described from the duty of candour. After all, we are talking about basic humanity and ethics. It is about telling people the truth about something that has happened and which might have caused them significant harm or might lead to significant harm.

We should remember that the bill's proposals on a statutory duty of candour are focused on the organisation and that a really important obligation that it places on the organisation is to support its staff. That should come across loud and clear. Therefore, the duty will have the opposite effect to the one that Mr MacKenzie described. It should make people feel more confident that their organisation has to step up to the plate and provide the necessary environment and support the culture that is required to enable them safely and humanely to fulfil what, for most people, is a professional obligation anyway.

The duty is not only about basic ethical practice and patients' rights—incidentally, I think that there should be reference to it in the Patient Rights (Scotland) Act 2011, because the bill is a strange piece of legislation for such a measure to sit in. Perhaps it could be inserted into the 2011 act. Anyway, as well as the fact that it is grossly unfair and unjust for people to be denied information about their or a loved one's treatment, the organisations that are prepared to act in that way are precisely those that end up being the subject of scandals, such as the Mid Staffordshire and Morecambe Bay scandals, and the many others that we have seen. If an organisation is not prepared to be open and honest with patients whom it has harmed, it is very unlikely to be one that will learn lessons to improve patient safety. In fact, not being open and honest with patients and their families is a scandal in its own right. Dealing with that issue will help patient safety and, I hope, avoid some of the other consequences that people are worried about.

The Convener: Do you want to come back in, Dr Hendry?

Dr Hendry: I just want to make a minor point of clarification. My answer to Mr MacKenzie was primarily focused on the wilful neglect proposals. I was not suggesting that people would end up in jail for not complying with a duty of candour. There is an interesting issue—although it is much less of an issue—around the duty of candour. That is largely to do with people not being sure when the duty will kick in and when they should be doing stuff. However, our real fear is about the wilful neglect proposals.

There is not such an issue with the duty of candour, provided that people are supported, properly educated and clear about when they need to follow it. I suppose that one burden might come for patients if there are overly enthusiastic people who tell everybody about every little thing that is going on. That might be slightly risk-averse behaviour. However, my main answer to Mr MacKenzie was directed at our concerns about wilful neglect and not the introduction of the duty of candour.

Dennis Robertson: I want to pursue the issue a little further. Having looked at the case studies that Citizens Advice Scotland provided, I am finding the discussion a little difficult to an extent, as I am the parent of a daughter who died and who did not recover from surgery. We have to look at the pathway of care. The issue that I want to examine is the unintentional aspect, or something that could have happened but did not happen. That is perhaps not neglect in itself, but it is an unintentional consequence.

When we looked at the reasons behind my daughter's death, we found that they were to do with the whole pathway, from her introduction into care in the medical profession. That was looked at independently, and there were outcomes. We got the outcomes, and we know that the process and procedures have been changed, which is saving lives. If we accept that there can be unintentional consequences, is that not positive, because it is a learning thing? We had a situation that we hope never happens to anyone else but, from it, a lesson was learned and there was a positive outcome. As grieving parents, if we look at what has happened and we are open and honest, we might not always be satisfied with the outcomes and answers, because that does not change the situation but, if we know that there is a positive outcome and learning from it, should we not welcome that?

10:30

Christine Lang: Our clients would certainly welcome that. A lot of the work that the patient advisers do with clients is about managing their expectations and what they want to gain from making a complaint. Often, people make a complaint to start the sort of dialogue with health professionals that you were able to have, to find out what went wrong and whether the outcome would have been different if something had been picked up at an earlier stage or if something had been different. Clients are certainly happy when they get an apology and they are told that lessons have been learned about what went wrong and that those lessons and best practice will be shared, so that it will not happen again. For many people who come to us, the main thing that they want is that the same thing should not happen to the next person. We would absolutely welcome anything that encourages that.

Dennis Robertson: My point is that putting something in legislation or statute perhaps does not change things. It might change things, but a process is already there that can be followed. We are reliant on the health professionals to reflect on what has happened and then to engage with the family. Is that not already written into the health boards and managed, perhaps satisfactorily? As parents, we might not welcome all the outcomes, but there is a learning thing, and that is already there. Therefore, do we need statute to make things better?

The Convener: I ask the panellists who wanted to respond to Mr Robertson's original question to deal with both questions together.

Dr Hendry: I completely agree with what Mr Robertson said there. It must be dreadful in that circumstance to have to engage and think about those issues. The MPS absolutely supports the idea of openness and developing an ability to speak to bereaved parents in that circumstance. We need to ensure that people learn from such things so that, if at all possible, nobody else has to go through those circumstances. We absolutely support that and we would—indeed we do—work with other organisations and through educational classes that we provide to try to support that.

The question for the committee is whether a statutory duty will make that better or will inhibit it, or whether it will be neutral. As I said, there are arguments for and against. On the duty of candour, at the end of the day, we do not fully know the answer. Obviously, that is what the committee needs to deliberate on and decide. Ultimately, I think that all of us at this end of the table agree that, when something like that happens and there is an adverse outcome, the family need to understand what has happened, and the staff at every level of the organisation need to be absolutely open. The point has been made on a number of occasions that medical care is now often a very complex journey that involves a whole lot of people at different points. For proper learning, everybody needs to be involved and be open and move forward.

As always with legislation, the worry is that, if it targets individuals, will that support the culture and outcomes that we all want, or will it inhibit that? The jury is perhaps out on that.

Peter Walsh: The duty of candour does not of course target individuals; it is focused on the organisation. We deal with thousands of families every year whose lives have been devastated by things going wrong in healthcare, and it is absolutely our understanding that they need to see the kind of outcome that Dennis Robertson described, and that is a great comfort to them. Most people just want the acknowledgement and the apology, and they want learning to arise so that it is less likely that the same thing will happen to someone else. Of course, for the most part, good organisations and good health professionals do that as part of their daily practice. However, we all know that a small but significant minority of professionals and organisations do not operate in that way.

Therefore, in effect, the duty will say that it is not an option to choose whether to follow good practice. At the moment, following good practice is recommended, but not following it is tolerated. The duty will make it much more likely that everyone will have a more constructive and positive learning experience, with the result that people will get a resolution to their concerns and the tragedy that they have experienced.

As I said earlier, if an organisation engages in such activity regularly and consistently and it is not given the option of opting out, it is more likely that it will take that learning and go forward and change things. Unfortunately, we have seen examples of situations in which those discussions did not take place. As well as that having the organisational implications of not learning how to make an incident less likely to happen again, the harm that is caused to families like Dennis Robertson's when they have not been dealt with in the way that his family was dealt with can be as devastating as the harm that is caused in an unintended patient safety incident.

It will be a win-win situation if we get the bill right and support it in the way that we would all like it to be supported.

Professor Britton: I have a brief comment to make in response to Mr Robertson's very personal example. I do not think that any piece of legislation can ever be drafted that enhances the value of a personal and sincerely given apology. I do not think that we can draft anything that will ever replace that. The best that legislation or policy or regulation can do is look at the processes that accompany that, so that an apology is given and, importantly, we review what happened—we look at the process to identify whether we can prevent it from happening again by putting in place an action plan.

In a healthcare setting, most boards in Scotland now have protocols that will allow a personal apology to be given without admission of blame or liability. In some cases, those protocols also allow practices and processes to be looked at. The question is the one that Dennis Robertson has posed: will the bill provide anything additional to what is already there? Although an organisation can look at protocols and processes, an apology has to be an individual thing. If an organisation were to send in someone who had not been involved in the case or who did not have some understanding of what went wrong in the circumstances, that would perhaps take away from the value and sincerity of the apology.

Richard Lyle (Central Scotland) (SNP): I turn to Peter Walsh's submission on behalf of Action against Medical Accidents. In it, you say that you have worked closely with ministers in England on the development of the duty of candour that applies there. You go on to say:

> "if it is introduced in the right way, the Duty of Candour will represent the biggest breakthrough in patient safety and patients' rights in Scotland's history and put Scotland amongst the world's leaders in its approach to patient safety."

However, you say that you

> "have some major concerns about how the Bill as currently drafted deals with the Duty of Candour."

You do not pull any punches in relation to section 21. You suggest amendments to the wording of the definition of incidents that should activate the duty of candour procedure.

Although it is early in the bill consideration process, what provisions do you think need to be changed? What steps are you taking to work closely with ministers in Scotland to ensure that we get the bill right, take account of the points that Dennis Robertson and others have made and thereby get the best system in the world? I also ask the other witnesses what steps they are taking to discuss the bill with the Government or other people in order to get it right.

Mr Walsh, your submission was very good. You did not pull any punches. What do you suggest that we should do to the bill to ensure that we get the best approach to patient safety in the world?

Peter Walsh: I am glad to say that we have had a positive relationship with Scottish Government ministers and officials. I have already held one meeting with officials who are working on the bill, and I was reassured to hear that the policy intention behind it sits neatly with what we ask for in our submission. It is perfectly possible to amend the bill and to frame the eventual regulations and guidance in such a way that they underline those points.

One of the key points for us is that we must be absolutely clear that potential harm, or harm that might arise in the future, is included. It should not be the case that the NHS or the nursing home conducts its own investigation and that it is only when, as the result of a rigorous investigation, it is found that harm has been caused or there was an unintended harmful incident that the patient or their family is spoken to. They should be involved at the very first stage when it is suspected that harm might have happened, so that they can be involved, if they want to be, in the investigation. Many of the investigations that we see were conducted with no input from the family, and when they see the investigation report, they say, "If you'd only asked me, I could have told you that it didn't happen that way," and it all has to start again. That is fundamental.

Training and support must be there from the beginning. We all agree about that. This is mostly about underpinning culture change and supporting services and staff to do the right thing. However, there needs to be a stick at the end. Otherwise, what is the point of passing legislation? We need to be clear about that.

There is a point about the definition of incidents. It is important—I understand that this is the policy intention—to include omissions. A failure to diagnose or a delayed diagnosis, when something is subsequently recognised, is an incident. It does not have to be a physical slip of the scalpel or something that we can physically see and define. It is something that has gone wrong in someone's care that has the potential to result in harm.

I agree with Professor Britton's point about apologies. When carrying out the duty of candour procedure, we would all want and expect there to be an apology, but we have a conceptual difficulty about requiring an apology. If families or patients feel that the only reason why they are getting something with the words "I apologise" in it is that they have to because it has been set in statute, there is a danger that the apology might be diluted.

Good practice is best dealt with in the guidance. Lots of good things could be said in the guidance about how to deliver information and how to make a meaningful apology. To my mind, an expression of sorrow or regret is not a meaningful apology. That is just human regret that something has happened. If that thing should have been avoided, we want people to take responsibility for it as well.

I totally agree with Christine Lang's point about support. We are talking about a very difficult time for people, and the patient advice and support service and specialist charities such as ours are well equipped to help with specialist support.

We pointed out a potential gap in the bill to officials and I think that they are minded to have a good look at it. When there was an unintended harmful incident, what will happen if the treatment comes to somebody's attention but they were not the provider of the treatment? Quite often, a GP will see or surmise that something went wrong in hospital treatment, or vice versa.

I am not saying that what happens in England is exactly the right way to deal with that, but the problem was recognised there and it is now a requirement that, if something comes to light about treatment that an individual received from another provider, people cannot just say, "It's nothing to do with me, so I'll keep my lips sealed." They have to go back to the original provider and say, "Do you know what? I think you need to have a discussion with my patient about X, Y and Z." The duty carries on, and that would be a nice way to close the gap in the bill.

We hope and expect that our constructive dialogue with officials will continue. They have indicated that they would like us to be involved in discussing the regulations and guidance when those are available. We hope to be involved in the training as well, to get it across to people that this is not something that they should be frightened of. They should welcome it, but they will need understanding and skills to do it well.

10:45

The Convener: Do any other panel members have comments?

Dr Hendry: On engagement, we had a helpful meeting to discuss our concerns with the Scottish Government group under Professor White that is drafting the guidance. Initially, we made the point that we made earlier today—that, if the legislation is going ahead, it is very important that we get the guidance right. I have been asked to join Professor White's group, to help with the drafting of the guidance.

The two big areas are definitions and monitoring. I will not go into huge detail, but a lot of that is about when the duty is triggered—what events would trigger it. That is particularly the case if we are to go as far as including omissions.

In my experience—I was a GP in Dundee for 10 years—the nature of practice is that people do not necessarily get everything right first time. If every patient who potentially had a serious diagnosis was immediately referred for investigation or treatment, there would be gross overinvestigation and the secondary care system would be brought to its knees. The question would be whether, if I had seen a patient two or three times with some vague symptoms and it turned out that they had a more serious illness, I should have diagnosed that a week or two earlier. That might have made no difference to the outcome.

The way in which I practise medicine is that I would have a conversation with the patient about the event and I would certainly not try to cover it up. If I had a statutory duty, would I need to get an independent doctor to critique my care and give feedback? From a GP perspective, I suggest that that would be unnecessarily or unworkably burdensome.

I do not think that such a process is what this should be about. I hope that the nature of the patient's relationship with their GP would not be based on that sort of thing.

It will be difficult for practices if they do not have adequate training and support and clarity in the definitions of the point at which an action should be triggered. Some of the suggested disclosable events in hospital make sense at one level, such as patients having to be transferred to intensive care unexpectedly, returning to theatre or being readmitted to hospital. I can understand the thinking, but it would not be helpful in a deteriorating situation if the clinician thought that the patient had better not go to the intensive care unit because that would be a disclosable event.

It is important to be clear about what the threshold of harm is. If someone independent is to critique an event, it has to be of a certain gravity.

To take Mr Walsh's point, involving the family and external people is absolutely right for very serious events but would be impossible for every single event. We know that there is a problem for something like 10 or 15 per cent of clinical events. Most do not result in harm, and it is difficult to predict future harm.

We are keen to engage with the Scottish Government to make sure that any guidance that comes out is practicable and supports the profession in delivering good care.

Christine Lang: We want whatever process is introduced to be as simple as possible for members of the public who are raising concerns or being made aware of the new provisions. It should not focus just on the impact on health professionals. For somebody who is unhappy about an event or is made aware of the new provisions, the process should be as simple and straightforward as possible.

Richard Lyle: I will concentrate for a minute on a point that Dr Robert Hendry made about trust in doctors. I trust my doctor implicitly, and most of the population do, but I take the point that doctors are not psychic and that when I walk in with something they need to do tests.

When we met Haemophilia Scotland and the Scottish Infected Blood Forum—Bob Doris referred to that—one lady said that she had not been told for 12 years that she was infected. A doctor should be honest and forthright and should tell patients exactly what is wrong. I know that some patients say, "I don't want you to tell me," but does Dr Hendry agree that, given the high regard that we have for them, doctors should be honest, forthright and up front with their patients at all times?

Dr Hendry: Absolutely—I could not agree more. As a GP, if I sat on the information that one of my patients had contracted hepatitis or a similar condition and I did not tell them, I would expect to be taken to task. Frankly, I would expect to be sent to the General Medical Council. I do not know all the stories, but keeping that information from a patient for 12 years is far from what one expects as reasonable conduct.

The clinical relationship and the way in which medicine is moving are about shared decision making. If there is no trust, the whole point of the exercise is lost. We have to ask how we can support and build that. Doing that is easier in general practice, or it certainly used to be but, sadly, one of the problems in primary care is that the situation is perhaps not what it was in my day. That might be an issue for another day but, if the whole relationship is to work and the patients are to get the best care, it must be based on mutual trust and respect. We are trying to support that as far as possible. That is a long way of saying that I agree with Richard Lyle.

The Convener: I think that Colin Keir has a question.

Colin Keir: My question has been answered.

Nanette Milne (North East Scotland) (Con): I apologise for arriving late this morning, convener. Would it be appropriate to ask the panel how the bill that we are considering ties in with Margaret Mitchell's Apologies (Scotland) Bill, which is going through Parliament? Should the duty of candour be part of broader apologies legislation and therefore be taken out of the Health (Tobacco, Nicotine etc and Care) (Scotland) Bill, or should the Apologies (Scotland) Bill be amended to exclude health and social care, so that that is left to this committee to pursue?

Professor Britton: I understand that Ms Mitchell's bill is looking at apology in its broadest sense, so it would apply across the board in all civil liabilities. We focus on the apology only in relation to health and social care provision. We have said something similar about the value of an apology, and the Law Society has questioned whether—only in a healthcare environment—Ms Mitchell's bill is required, because we have the Compensation Act 2006 and we have NHS board guidance, policies and protocols, all of which are moving to change the culture to allow an apology and an explanation and for an action plan to be drawn up to ensure that such an incident does not happen again.

Peter Walsh: For what it is worth, I have similar feelings about the Apologies (Scotland) Bill. We are not sure that it is needed, because it is already accepted that an apology is not an admission of liability. The other piece of legislation that the Health (Tobacco, Nicotine etc and Care) (Scotland) Bill could tie in with is the Patient Rights (Scotland) Act 2011, because we are talking about what is, in effect, a fundamental patient's right that most people on the street would expect already exists, although it will not until the bill is passed.

I am not suggesting that the provisions should be taken out of the bill and that you should wait to change the 2011 act, but some kind of amendment to make this sit in the 2011 act, as well as passing the bill as quickly as possible, might be a more appropriate way of proceeding.

Christine Lang: My concern is more about the terminology, because the 2011 act refers specifically to patients. In social care, I do not know whether people would define themselves as patients. They would probably define themselves as service users or use another definition, so there would be a terminology issue if you proceeded in that way.

Professor Britton: Patient rights look at the rights of the patient as an individual. The bill's aim is to look at a duty of candour as it applies to organisations. I do not think that they should be conflated.

Nanette Milne: It was helpful to get that on the record.

Mike MacKenzie: If I was to put on the hat of a health economist, it would seem that the bill could consume a certain amount of health resource for compliance, training and so on and so forth. Given that we have finite resources and budget challenges, is there a concern that that would take resources away from other aspects of healthcare? To what degree might that be a negative effect of the bill?

Dr Hendry: On the financial assessment, if you are looking to support the changes, it would be useful to spend some money on education. Frankly, some of the money might be better spent on Christine Lang's colleagues in CAS, so that they can support patients, help them get through the process and have a dialogue with the providers if something went wrong. If we are looking to have a more joined-up solution rather than add an administrative burden, having practical support for patients when they have queries or need support or some understanding may be a more appropriate way of spending money.

Professor Britton: Section 21 of the bill says that involved persons cannot give an opinion on an incident. That may impact on resources. If we imagine the scenario in a busy hospital, one person might be treated by a chain of professionals from the moment that they walk in the door. Supervision might be given by a consultant who had not met the patient or dealt with them directly at all, but the consultant would know the context and would be able to comment on the incident. Would they be excluded from doing that? If they were excluded, there would be resource implications. The hospital would have to find somebody else, who would have to take the time to come in and examine the whole situation without having first-hand knowledge.

Other examples might include a small GP practice. How would somebody who was uninvolved get to understand the consequences of an incident? In the case of single care in a social setting, perhaps involving caring for someone in their own home, bringing in somebody who is completely uninvolved would be challenging in many ways, not least as regards resources. They would need to be trained, they would need to understand the situation and they would need to get the context.

When we are looking at the definitions, the idea of the extent of involvement could be usefully reviewed to make better use of the resources and of the expertise and knowledge of the person who is dealing with a case.

Peter Walsh: As far as I can see, there are two areas where there could be resource implications. One has just been mentioned—it involves seeking an independent health professional’s opinion. We raised that point in our submission and we discussed it with colleagues. I understand that it is not the intention that every incident that might be subject to the duty of candour procedures should be independently reviewed, with a decision being made by an independent clinician. We certainly hope that that is the case, because having every incident independently reviewed would be burdensome and unnecessary. It would cost money but, more important, it would delay health professionals from getting on with what most of them already do—the right thing of giving their patients explanations. We do not want to get in the way of that. However, if there is any doubt, going to an independent person for a second opinion is certainly a good idea. That would have a modest resource implication.

11:00

The other resource implication relates to providing training and support, particularly initially, to get things off on the right foot with widespread awareness in a way that—sadly—did not happen from day 1 in England, and to providing a certain amount of on-going training and support.

That said, although there are resource implications, one has to remember that we are talking about fundamental stuff that people should be doing already. If they are not, we or they need to invest in that. It is fundamental to patient safety, and if the bill contributes to improvements in patient safety, the savings from it will far outweigh the modest resource that is put into it.

Mike MacKenzie: Will you elaborate a bit further on the savings?

Peter Walsh: The savings would come from improving patient safety. If a health board was prepared to sweep such an incident under the carpet and not to tell the patient or the family about it, for example, it is very unlikely that there would be learning internally to help to prevent such an incident from happening to someone else. If the bill contributes to changing that culture and getting a genuine learning culture, so that there is learning from each and every incident, the payback will come in preventing extra bed days, extra treatment and extra litigation in the future. Of course, we aspire to improving patient safety as a basic function, right and ethical practice in any case.

Mike MacKenzie: I—

The Convener: Are there any other responses to the original question?

Mike MacKenzie: Convener, I was merely going to ask whether there has been any analysis that attempts to quantify the effect of the lessening of failure demand, which has just been touched on.

Peter Walsh: There has not been any yet in relation to the duty of candour specifically, because it is so new. However, there is a mass of literature and research on the positive long-term savings that can be—and in some instances have been—made through improving patient safety. The duty of candour is part of that; it is not all of it.

The Convener: Bob Doris has our last question.

Bob Doris: The witnesses will be delighted that it is not actually a question; rather, I want to reflect again information that we received from the Scottish Infected Blood Forum, Haemophilia Scotland and the Hepatitis C Trust. I did not want to intervene during the discussion and questions on receiving a meaningful apology, but it is reasonable, given that those organisations will be following this evidence session, to put it on record that they were pretty clear in relation to infected blood that, although they really appreciated apologies coming from the likes of the First Minister and the Cabinet Secretary for Health, Wellbeing and Sport, it was much more meaningful when the Scottish National Blood Transfusion Service said something.

It is important to put it on record that those organisations felt that getting a corporate apology at the top was meaningful in respect of system changes and learning. I think that Unison said something about that last week in its evidence. We received information that getting the apology as close to where the incident took place is far more meaningful for the people who are affected.

There was not a question in what I have said, but I think that those organisations would like that to be reflected in the *Official Report*, given what was discussed.

The Convener: That concludes this evidence session. On behalf of the committee, I thank the witnesses very much for their attendance, written evidence and contributions to our inquiry.

We will suspend the meeting and set up the next panel.

11:03

Meeting suspended.

11:09

On resuming—

Palliative Care

The Convener: Item 3 is an evidence session for our palliative care inquiry. Before we hear from the witnesses, I put on record our thanks to the staff and service users at Rachel House in Kinross and Ardgowan hospice in Greenock, who hosted visits from committee members this week. I, and the members who accompanied me yesterday, found our visit to Ardgowan hospice extremely helpful and useful, and having spoken to Rhoda Grant, who is not here today, I know that she had the same thoughts about her visit to Rachel House. We thank everyone who made possible our engagement, which has made this inquiry all the more meaningful.

I welcome our witnesses. Amy Dalrymple is head of policy at Alzheimer Scotland; Trisha Hatt is senior service development manager for Scotland at Macmillan Cancer Support; Richard Meade is head of policy and public affairs at Marie Curie; and Maria McGill is chief executive of the Children’s Hospice Association Scotland. We do not expect opening statements, and in the interests of time we will move straight to questions.

Malcolm Chisholm: I thank the witnesses for their detailed written submissions, which were extremely useful. I will focus on a couple of points in Macmillan’s submission that introduce some of the issues. Macmillan says:

> “There is a growing misperception that palliative and end of life care is a generic speciality which can be universally applied across all conditions”.

You go on to say that

> “cancer creates a unique set of challenges”,

and that there is a

> “Misperception that all cancer patients receive good palliative and end of life care”,

although studies have found that

> “between one quarter and one third of cancer patients had not been identified as having palliative care needs.”

I think that all the submissions place legitimate emphasis on the need to extend palliative and end-of-life care to many conditions, rather than just cancer, and many of them suggest that there is a role for generalists in palliative care. I want to explore the potential for tension between those two areas—although I am sure that there is really no tension, in that they cover the totality of the issue.

Trisha Hatt (Macmillan Cancer Support): We are here to support the provision of palliative care for all on the basis of need, not diagnosis. In cancer services there has been a lot of emphasis on delivering palliative and end-of-life care, but a growing number of patients with a diagnosis of cancer are living longer, as you know, and we know from talking to patients and their families that people do not always get the care that they need, particularly during the palliative and end-of-life care phase.

Macmillan has a lot of experience and would like to help to extend palliative and end-of-life care across all diagnoses. We are in a unique position, in that we have had a lot of focus on palliative and end-of-life care and our clinical nurse specialists have a lot of skills. We support the upskilling of generalist staff. There are a number of cancer patients who receive palliative and end-of-life care from generalist staff across the piece, whether that is in their home, in hospital, in a care home or wherever they need care.

Malcolm Chisholm: Do the other witnesses want to respond? Does Richard Meade want to comment?

Richard Meade (Marie Curie): You raised the issue of palliative care being a generic form of care. Palliative care is one of the truest forms of person-centred care, and it is important to emphasise that it can be very different, depending on the different patients who receive it and on their families. The needs of the patient and their family should always be put at the centre of the care. The care should be holistic; it is often about not just medical interventions and pain and symptom management but emotional, spiritual and psychological support, as well as planning—what matters to the person and what they want to happen in the time that they have.

11:15

Maria McGill (Children's Hospice Association Scotland): First, I thank the committee for enabling the voices of children and families to be brought to the inquiry.

Palliative care for children and young people is perhaps a little different in several ways. One relates to the range of conditions. We in children's palliative care see more than 400 conditions but few children and young people with cancer. In fact, the latest figures that I have, which are for 2009, show that of the 450 children who died then, only 36 had cancer. We in children's palliative care meet a different situation. That said, it is important that every child or young person who has a life-shortening condition receives the best-possible quality of care wherever they are in Scotland and whenever they need it.

Amy Dalrymple (Alzheimer Scotland): Our view, which supports what Macmillan is trying to say, is that the literature on palliative care and the experience of palliative care tends to be more about cancer than other conditions. The research into dementia and palliative care is still developing—it is at a relatively early stage.

We suggest that palliative care is not generic in itself. You need the two specialisms—the condition specialism and the palliative specialism—to come together and to work together to give the person-centred care that Richard Meade described. All four of us here probably agree, but we come at the answer from different places.

Malcolm Chisholm: I am happy with those answers.

Dennis Robertson: One of the problems is that palliative care seems to mean different things to different people, even within the medical profession. Yesterday we heard from a specialist nurse in palliative care who said that when such nurses talk about palliative care to junior doctors, the junior doctors sometimes think that they are talking about end-of-life care. When we talk about people requiring palliative care, the perception in the wider community is about end-of-life care rather than the holistic care that Richard Meade talked about. Do we need to get a clear message out that palliative care is a person-centred approach to the needs of the individual, that it is not necessarily end-of-life care and that it is not just for cancer patients?

Richard Meade: I—

Amy Dalrymple: Well—

The Convener: It would be helpful if I was allowed to convene. I let Malcolm Chisholm get away with it earlier but you see how quickly people take advantage and call out their answers. I shall prevail. Amy Dalrymple will go first.

Amy Dalrymple: Thank you, convener.

For dementia care, we are looking at the development of what we call an extended palliative phase. Prognosis and identifying the end-of-life phase are difficult with dementia, particularly when somebody is dying of dementia, rather than with dementia. Someone might be dying of something else but dementia is having an impact on their experience, or they might be dying of dementia. If somebody is dying of dementia, it is hard to identify their end-of-life phase. We therefore encourage a palliative approach a lot earlier.

We need to work out how we approach the language around that when we speak to the family and the person themselves because of the conflation of palliative care with end-of-life care. That comes from the palliative care approach being developed with specific conditions in mind.

We are trying to broaden it out to other conditions. We need to look at how we adapt palliative care and the conversations around it in order to enable families and people who have those conditions to be comfortable with and accept it so that they can access it and the benefits that it might bring.

Richard Meade: I would like to pick up a couple of points. There is a comparable symptom burden in all types of terminal illness that palliative care can support. Palliative care should be introduced from the point of need, which can be very different depending on the person and their condition or conditions. It could be needed for years, months, weeks or days. That is a really important point.

Barriers have been mentioned, and we need to make sure that there is enough training and education not just for specialist palliative care practitioners but for generalists, such as GPs and district nurses, and for hospital consultants in different specialisms to ensure that they understand how to link in with palliative care when the time is right for the patient. Sometimes it is just about starting the conversation such that when someone is seriously ill, there is a point at which somebody talks to them about their condition and about what matters to them in the potentially short time that they have left, and plans for that.

It is part of a wider issue about having open and honest conversations. That is not just an issue for our health and social care professionals; it is a societal issue. We need to have more open and honest conversations about the end of life and being terminally ill, what that might involve and how we approach it.

Maria McGill: I agree whole-heartedly with Richard Meade that this is a societal issue. Open and honest conversations are incredibly important for everyone, particularly the children and families whom I represent. For children, their condition's timespan might extend into years, so palliative care for children is often around for years. Palliative care should be involved at the point of need. One of the barriers is that perhaps the benefits and positive impacts that palliative care can bring to a child with a life-shortening condition are not as well known as they might be to families and particularly to the professionals on whom we rely for referrals. There are a multitude of barriers, one of which is around the willingness of all of us in society to have open conversations about our wishes in terms of our place of care and place of death, and, particularly for children, about the benefits of early referral to palliative care.

Trisha Hatt: I agree with what everyone is saying about the palliative care agenda—it is an issue for everyone. It is everyone's business; it is not just the business of clinicians and social care staff. It is about the public being able to find it in themselves to understand at what stage their needs become palliative. We can use things such as holistic needs assessments, which take a person-centred approach and identify that person's real needs, which could be housing or other things that are not key to their diagnosis. Palliative care could start very early after diagnosis. As Richard Meade said, it is different for every person.

Richard Meade: People's palliative care needs can change throughout their condition. They might need some quite intense support at the start, and then have a period of needing fewer services. Palliative care can come in and out. People do not have to get a certain level of palliative care throughout; it can change.

The Convener: Dennis, do you want to come in?

Dennis Robertson: Thank you, convener. I was waiting to be asked.

The Convener: You have been asked now. Are you going to continue to waste the precious time that we have? [*Laughter*.]

Dennis Robertson: Trisha Hatt stated that palliative care is everybody's business; Professor Clark said that too. He also said that Scotland is providing some of the best palliative care in the world, although he recognises that there is still a lot to be done. In recognition of that—and picking up Richard Meade's point that things change—I would like to know whose business it really is to identify when a person on that pathway requires palliative care. They could be getting care from someone else, such as social care. What is the trigger for palliative care and who identifies the need for it? What steps do we need to take to ensure that people get the care that they require when they need it?

Trisha Hatt: That goes back to upskilling generalist staff so that people right across the piece have the skills to recognise when the person's needs change.

An example of that is the improving the cancer journey service that we support through Glasgow City Council and NHS Greater Glasgow and Clyde. That service identifies the person's needs and signposts them to, or directs them back to, a clinician—whether that is the specialist, the general practitioner or the district nurse—or social care.

The question is who the relevant person is to support the person at that time. The issue goes back to ensuring that staff across the piece are skilled in recognising what support is required, whether that is done through a conversation, through sitting down and supporting someone with a holistic needs assessment or through anticipatory care planning. All those things get taken into consideration in identifying the proper support. It is everyone's business.

Amy Dalrymple: I was interested in the distinction that Dennis Robertson made between social care and palliative care. At the moment a full range of professionals is involved in delivering palliative care who do not necessarily recognise that they are doing that. There is an argument to be made that all the care that is delivered in relation to dementia is palliative because it is not curative, to use a stark definition of palliative care.

Dennis Robertson asked about the trigger for bringing in specialist palliative care services to provide care or—preferably, for us—to support the professionals who are already providing care to continue to do so. I note that that continuation of personnel is important for people with dementia and other cognitive difficulties. Palliative care needs to be brought in in a multidisciplinary way by the whole team. In an ideal world, the team works in a co-ordinated way to provide the health and social care supports for the person with dementia, with everyone interacting with one another and helping the person to have the best quality of life. When the palliative care specialism is identified as being necessary to support that delivery of care and maintain the person's quality of life, it needs to be brought in. However, that needs to be done in a team way; it needs to involve the person, where possible; and it needs to involve those who are closest to them.

Richard Meade: It is everyone's business. A range of screening tools is available to help and support professionals to identify the triggers for palliative care. Again, it goes back to education and training. We need to ensure that, when we have good, useful tools, their use is supported and they are widely used. We must make sure that health and social care professionals have the training supports to use them.

Maria McGill: Dennis Robertson asked about triggers and identification. It is really important that all health and social care professionals have an awareness of the benefits that children's palliative care can bring. Referral to a palliative care service for a child with a life-shortening condition does not mean the end of curative treatment. It simply means that that child and family have access to a life-enriching experience and to professionals who are perhaps better able to manage symptoms, who have the time and the ability to sit down with the family and understand what matters most to them and who can work with the entire team around the child to help to make that happen. Everyone needs to have an awareness.

There are some identification tools that can be used for adults, but there are fewer in children's palliative care. It is a newer specialism within palliative care, so we have some research to do to get those tools right.

Trisha Hatt: One of the triggers involves the carers, whose needs must be identified, too. The trigger can come when it is identified that a carer who frequents one of our information and support services, for example, or the GP service is not coping, because that is when we can identify that the person for whom they are caring has other needs.

Bob Doris: I am interested in what Amy Dalrymple said about social care naturally developing into palliative care. A lot of palliative care goes unrecognised as part of good-quality social care.

I understand that, where specialist palliative care is provided—other witnesses can give powerful examples of that—there is a perception that it kicks in at some point. However, a few of us will have personal experience with our families in which it was not a case of something kicking in but, particularly with dementia, a general deterioration over time that also comes with getting old and frail. Dementia also brings significant issues, whether in the general social care sector or a specialist unit.

The issue is how we map the good-quality palliative care that exists out there. For example, vascular dementia is a condition in which people unlearn basic things, such as being able to communicate or to swallow, eat and chew. How do we map out and support the good practice in dealing with that condition? I suspect—I draw on personal experience in saying this—that a significant number of people in the general social care residential sector have additional palliative care needs. How those needs are being provided for is a mixed bag. I am not sure that local authority and third sector organisations are able to develop a system to identify where those additional care resources are needed or to draw in other agencies to support that work.

I am aware that I am talking specifically about dementia, but how do we map out and quantify practice? I suspect that, over generations, there has been an unmet need in the residential care sector, so it is okay to admit that there is a gap there and work towards addressing it. How do we provide the evidence and then the method by which to deliver and improve the quality of care for people in those situations?

11:30

Amy Dalrymple: I will have to try very hard to provide a brief response, but I would be happy to have a full meeting with you on the issue if you are interested. We have been looking at the issue in a lot of detail. Towards the end of October, we will publish a full report on how we envisage such care should be provided. I will, of course, send a copy to committee members.

Dementia is underdiagnosed in residential care, which means that there are people in that setting who we do not know have the condition, which means that they will not necessarily have their needs met. As you say, there are pockets of good practice. A hospice may join up with a care home. There may be good relationships between, for example, a community hospital and a care home, and they may share their skills.

We need to bring in the health element, too. For example, you talked about people with swallowing problems. A speech and language therapist is needed to deal with that. The responsibility for that would sit not necessarily with the local authority but with the health board. We hope that the integration of health and social care, including the budgets, should lead to more co-ordinated support. It is crucial that the partnerships exist with the third and independent sectors to ensure that there is co-ordination. I pay tribute to the independent care sector for recognising that and for starting to do its bit in making links with the new health and social care partnerships.

We suggest that a dementia practice co-ordinator is required to co-ordinate all the parts of care that are needed to make sure that someone with dementia is supported in the best way. On your example of vascular dementia, we must make sure that staff in residential care homes are not asked to do a complex care support job unsupported or untrained. They need access to training and specialist support to enable them to provide the care that they are expected to provide.

The Convener: Does anyone else wish to respond?

Bob Doris: Sorry, convener, it is your job to bring in other speakers, but I wondered whether the other witnesses would agree that we have to realise that palliative care builds up gradually over time and that we must get better at quantifying it. Sometimes, we quantify matters when something major happens, such as when a diagnosis is made or when there is a significant downturn in people’s health. That is when palliative care kicks in—that is when we start to do the bean counting of palliative care, if you like.

I will come back in later, convener, but I wanted to make that general point.

The Convener: It seems that you will prompt some responses from the witnesses. When you get those responses, we will see whether you want to come back in.

Maria McGill: I agree with Bob Doris that palliative care is sometimes prompted by a significant event or a diagnosis. Because palliative care for a child can extend over a significant period, it needs to be provided from the beginning. For example, a child might have a series of short planned breaks in one of our hospices, to enable their family to continue to care in the community where they want to be. A family can be supported by a package of care and the CHAS at home team, so that they have access to specialist expertise as and when they need it. Sometimes, a series of short planned breaks over a number of years is enough for families, who describe such breaks as a lifeline that enables them to continue to cope at home. As things change, as they often do, we can come in—seamlessly, we hope—to support families with specialist support. We also support the team around the child, which is an incredibly important part of the work.

Trisha Hatt: In relation to transitions and considering risks for people, all of us, including clinicians and social care staff, have a lot of experience. We can know that at some stage a person will require palliative care, so it is about identifying that need early on. We use the tools that we talked about to ensure that support is in place before we get to the crucial point, so that things do not fall through and someone has to be admitted or their choice of place of death is not adhered to. It is about having a single point of access, particularly for people in residential care homes, to the range of care and support that is out there.

Richard Meade: I think that we all agree that there are great examples of care in social care settings, as well as in primary care settings from GPs and district nurses, and that great care can be provided without the need to refer to specialist palliative care.

The bigger issue that is being highlighted is the lack of data and information on the true picture. For example, I think that there are just short of 12,000 people on the palliative care register, but it is estimated that 40,000 people who needed palliative care die each year. Where are some of those people, and how can we get to the true number? A big part of the issue is the need to do more to identify people who have palliative care needs, whatever setting they are in. That would help us to understand where good practice is going on, where there is unmet need and what we can potentially do to meet need and improve care.

The Convener: I want to go back to the triggers for referral. In Greenock yesterday we heard that people had referred themselves through word of mouth, not to access palliative care—although I suppose that it is palliative care in the broadest sense—but to access transport and support services to get chemotherapy and radiotherapy in Glasgow. Even when people were accessing a service, it was difficult to get them to confirm who had referred them.

People seek palliative care because they have knowledge of it, and we know that palliative care is more accessible when someone has cancer. There is a difficult discussion to be had about the move from curative to palliative care when people have chronic obstructive pulmonary disease or heart disease, for example. In some cases, when people move on to palliative care they think, “That’s it. They’ve done all they can for me and now I’ve been sent home”—the witnesses will have heard all of that. Some people do not want to avail themselves of palliative care because of that perception, and others do not know about palliative care. There are people who would benefit from palliative care who are not getting it. It is the committee’s job to try to pick our way through all that.

Richard Meade: It is important to say that access to palliative care sometimes comes down to the healthcare professional that a person sees. There are examples of great care being provided by general practitioners who refer people for not just specialist but generalist care. If a GP is prepared to sit down with the person and have an open and honest conversation about what is important to them and what they might need, the person gets good care. However, that is not happening in every setting.

Trisha Hatt: The convener expressed the opinion that everyone who has a cancer diagnosis gets access to palliative care. We know that the numbers are increasing. Thankfully, people are living longer due to good research and treatment, but some are living longer with difficult problems and increasing palliative care needs.

There are good models of joined-up care out there. As I explained earlier, the improving the cancer journey service is one example that has been driven forward by social care. That is about identifying people when they are diagnosed, which is when we can start to do the holistic needs assessment.

Patients say that, generally, they are well cared for. They have lots of care, but their outside needs, such as their housing, spiritual or family needs, are not always addressed. We need to look at examples of good models of care like that.

The Convener: I hope that I said that someone who has cancer is more likely to get palliative care.

Trisha Hatt: Yes.

The Convener: We understand that and recognise that there is an unmet need even in that area. There is a challenge in extending that principle right across the board and whether that is possible.

Trisha Hatt: Absolutely.

Maria McGill: I remind the committee that the situation with children who have cancer is different in palliative care. Excuse me for reminding you.

I also want to build on the data that Richard Meade talked about. There is some good news around data in that CHAS, supported by the Scottish Government, commissioned research from the University of York, which is due to be published in November. It will tell us the number of children and young people in Scotland who have a life-shortening condition and where they are based by health board. It is a point-in-time exercise and it will be incredibly useful. The numbers that we have at the moment tell us that there are about 4,000 such children at any one time. CHAS saw 400 children last year, but we think that the research will tell us that there are many thousands. We have much work to do to make sure that every baby, child and young person can have access to the palliative care that they need when they need it.

We also need to bear in mind that there is a choice. With some families that I know of, coming to a hospice is not right for them. Our service works hard to be flexible so that we can accept the child into our care and make sure that they have access to it, but support them in their home. The family can still have respite and the child can still have outings and experiences that they might not otherwise get. That all happens outwith the hospices. We give families the choice and ensure that our services are child and family centred.

Richard Lyle: I put on the record my thanks for the excellent work that all your organisations do for real people in Scotland.

Richard Meade talked about good-quality data. I will refer to a quote in the Macmillan submission that I was concerned about at first, although I later realised why it had been put in. It says:

> “A recent English study found half of all patients dying at home received no/partial pain control. This must improve.”

However, the footnote shows that that is from the

> “National Survey of Bereaved People (VOICES) 2014”

and that

> “this data is not collected in Scotland”.

I know that that was put in as a long bowl to get someone like me to ask why the data is not collected in Scotland. Trisha Hatt’s submission says that 10,800 people have unmet palliative care needs and Richard Meade says that the figure is 12,000. Some people say that no one knows, and some say that it is 20,000. How do we collect that data? If someone tells me that I have cancer, I expect that I will be put up on a board and told that I will be seen by so-and-so, so-and-so and so-and-so. Why is the data not being collected in Scotland? Why do we not have the exact statistics that we need to ensure that the great work that you guys are doing is carried on and that people in Scotland get the attention and care that they deserve?

11:45

Richard Meade: I will try to unpick some of that. We do not have an accurate picture but we have best guesses and estimates, and we can use the palliative care register as an indicator. We need to see much more movement in the area of data. I know that David Clark picked up on that in his oral evidence and in his report to the committee. Identification is a big part of getting the data; we must ensure that we pick up those who have palliative needs, whether through the palliative care register or something else.

On how we might achieve that, the Scottish Government has committed to producing a strategic framework for action on palliative and end-of-life care, which will be published by the end of the year. I am confident that capturing data will be a big part of the framework, which will be very helpful.

I turn to the types of data that we need, and that brings me to Richard Lyle's point about VOICES, or the views of informal carers—evaluation of services survey. We need to see the quantitative data because we need to understand the numbers with regard to how many people need palliative care, when they get it, the kind of interventions that they receive and the outcomes. However, we also need to understand the quality of that care, particularly when we are talking about patients' personal outcomes in terms of what matters to them and what they want in the time that they have. We need to measure that as well, which is where VOICES is useful, because it asks bereaved carers about the care that their loved ones received, which is important information.

To be fair, Jamie Hepburn, the Scottish Government Minister for Sport, Health Improvement and Mental Health, committed in May to look at introducing VOICES work in Scotland, primarily at a local level. We fully support that and hope that the Scottish Government develops it and takes it forward. If we can get a VOICES survey in Scotland that can develop a baseline for what quality palliative care looks like, that would be as important as the quantitative data.

Trisha Hatt: That shows us that, on the data, there are already numbers available. However, we all agree that we need baseline data. We have GP palliative care registers, but we need to understand why some patients are not registered on those. Is it because they are in a care home and the staff feel that they need to refer them to a specialist service to get them on a palliative care register? I agree with Richard Meade that we need to look at a number of things. Having the support of the Scottish Government is fantastic, because it will get us together in gathering the information that is out there.

Maria McGill: It is perhaps a reassurance that we will have the data for children next month, so children and young people's palliative care is perhaps leading the way in that respect. We are delighted to be able to do the work on that with the University of York. As David Clark said last week, the data will allow us to begin to develop and test some models based on evidence. We can assess what is the best model of care that, in the financial circumstances, can be developed across Scotland to meet the needs of those children and young people.

I support the use of VOICES in the way that was described. VOICES has been used in England for more than 10 years, and Professor Addington-Hall has done a remarkable job with that work. However, my understanding is that it is not used for under-18s. If we are going to use that work in Scotland, we should consider developing it to ensure that it captures every death.

Amy Dalrymple: On the data point, it is really hard to see how many people with dementia require palliative care and how many people's dementia will impact on their experience of palliative care. However, there will be people whose very mild dementia will not impact on their experience of palliative care so much.

There are probably about 46,000 people with a diagnosis of dementia, but the trajectory of dementia is so variable that it is very hard to predict how many of them will be coming to the end of their life. However, depending on the type of dementia that they have, we would want to introduce elements of palliative care early on before end-of-life care. We have to look at where those people are, which will have an impact on how the care is delivered. At the moment, most people with dementia who are coming to the end of their life are in a care home, but increasing numbers are in their own homes and significant numbers are still in hospital. Very few people with dementia are in hospices, even compared with the general population in hospices. In general, hospices are not accessed by people with dementia. That happens to a small extent, but we are talking about only a very small number of people.

Therefore, it is extremely hard to work out how many people with dementia have unmet palliative care needs. The Scottish Government is doing some work to look at the incidence of dementia and when in people's lives they get dementia. As older people get it, that will be nearer the end of their lives, so people will spend two or three years living with it rather than between five and nine years, which is the usual trajectory for Alzheimer's.

I cannot give you an answer. Although a lot of work is being done, a lot more still needs to be done. We still need an up-to-date study of prevalence in Scotland. We do not have that at the moment. We use the European figures to give us the best outline that we can get, but it is difficult to pin down the figures for Scotland. The fact that dementia is underdiagnosed is one reason why it is harder to pin down those figures. We need to improve our diagnosis rates so that we can improve planning for palliative care.

Richard Lyle: I have got the excellent answers that I wanted—thank you.

Nanette Milne: I want to ask about respite care, which Maria McGill mentioned briefly in relation to CHAS. I know that Maria is very familiar with Robert Watson's "What About Us?" campaign. In his petition to the Parliament, he makes the point that the majority of adult hospices provide palliative care but no respite. He believes that the importance of respite cannot be overestimated and that the provision of adequate and appropriate respite should be seen as an integral part of palliative care, rather than an add-on. I would be interested to hear the panel's comments on that.

Maria McGill: I am happy to start; I am sure that others will want to join in.

I am incredibly proud of Robert Watson's achievements in lodging his petition and managing to get a parliamentary debate on the issue. I was very proud of Parliament the night that it was debated.

You are right that respite is incredibly important. That is certainly the case with this particular group of young people—there are around 90 young people in CHAS over the age of 18 who are likely to make the transition to adult services over the coming years. For some, the issue is about having a place to go for respite, whether that is an adult hospice or another facility. Some young people want to embrace self-directed support, which they will use to have a different form of respite.

We have been working with every adult hospice in Scotland, bearing in mind that it is necessary for the young people concerned to have a choice about where they want that respite to be. We are working with Marie Curie in Glasgow and have some focus groups coming up with young people and their families to help us and Marie Curie to understand what could be provided for young people. In addition, we are working with Leuchie House in North Berwick to test a break there. Our staff are working with Leuchie House staff and a group of young people to find out whether that is a possible model.

We are seeking to find respite for this group of young people in a variety of ways. Some of them are supported by CHAS, but the number of young people who live in our communities with life-shortening conditions is increasing. When they were diagnosed, it was thought that they were likely to die before they reached adulthood but, with medical advances, they are living much longer. In England, the number of such young people has increased from 19 per 10,000 members of the population to 35 per 10,000, so there is perhaps a significant and hidden need.

Richard Meade: This is a good opportunity to talk about carers. I agree that respite is very important, but the role of carers in caring for people who are terminally ill and at the end of life often goes unrecognised. I know that the committee has heard from us on the issue through its work on the Carers (Scotland) Bill, but it is worth reiterating that a live-in carer is the single most important factor in whether someone can die at home, which is often what people would prefer.

Many of those carers do not get the support that they need. Often they are not identified as being carers by statutory services—whether by GPs or by social care—and often they do not identify themselves as carers; they simply see themselves as a family member, a loved one, a wife or a husband. The support that we give carers is really important in ensuring that the good care that a person is getting at home continues.

Respite care for carers is particularly important. It could be for just a few hours so that a carer can get away to get some shopping or to have a bit of personal time or it could be a bit of support overnight so that they can get some rest. As part of this inquiry, we need to look at the role that carers play to ensure that good palliative care and good care for people can continue.

Amy Dalrymple: We have been talking to carers as part of the development of our work that I talked about earlier, and they say that they need support in two ways. They need support to do the job of caring, which includes providing palliative care—we talk about social carers providing palliative care but informal carers are providing it as well. Carers also need support to be themselves—to have their own life and to maintain their quality of life.

We know that carer stress and the breakdown of the informal caring relationship is the single biggest factor that precipitates somebody accessing or moving to a care home. We want people to maintain being able to be at home if that is appropriate for them and as far as that is their choice. We also want moving to a care home to be seen as a positive choice, not as something that happens just because of carer stress. That means that we need to be able to support the carer as well as the person with dementia.

Our carers talk about the need for respite. Respite for somebody with dementia normally takes place in a care home rather than in a hospice. At the very end of life, somebody is likely to be in a care home anyway, so the issue is almost the other way round and is about making sure that the carer remains involved in providing care when the person is in a care home.

When somebody is at home, the carer needs respite and, as Richard Meade says, it needs to be flexible. It does not necessarily need to be for one week every six weeks; it might need to be on a Friday afternoon every week to enable the carer to go out and do things—to see their friends, play football or whatever it is that they want to do—to enable them to maintain their own resilience.

The system has an interest in ensuring that respite is provided so that carers can maintain their resilience and keep doing the caring role, as the system really relies on those carers. Therefore, respite is really important.

The other thing that carers for people with dementia often say that they would like is support to be able to do things with their partner or parent—the person they are caring for. It is not respite as such—it is not a break from the caring role—but support to be able to go on holiday or to have a day out as a family, so that needs to be considered alongside respite. It can play the same role so it is important that we think about that as well when we talk about this issue.

Often care homes provide respite, but it is important to be able to provide respite at home and to adapt to the needs of the person with dementia and the carer. It is about maintaining continuity. If somebody gets confused when they move to a different environment, they might start becoming stressed and exhibiting signs of stress behaviour. To maintain their sense of security, it is important that respite can be provided at home.

I hope that that feedback is helpful.

Trisha Hatt: Respite is really important for people and we need to identify the need for it as early as possible. People are affected by cancer right across the age spectrum, so it is about being innovative in looking at ways of providing respite so that it is not just provided in hospices or care homes. It is about looking at what is out there and at what we can do with support from volunteers, through programmes such as the Macmillan helping matters programme. As Richard Meade identified, people might just need respite for a couple of hours every other day or a couple of times a week. Those are the things that parents and families tell Macmillan. They want the need for respite to be identified early on so that it does not just come at a critical point in their care journey.

12:00

Maria McGill: To go back to the issue that Nanette Milne raised about young people, respite has a dual purpose. Often it is mums and dads who care for young people, albeit with a care package, and respite is incredibly important for them so that they can participate in life and socialise with people their own age. However, the young people themselves are often dependent on mum and dad or a care package, and if young people in their late 20s have to go to bed when the carers come in, which is sometimes at 7 or 8 o'clock, or when mum and dad can help them to bed, society is not enabling young people who have a life-shortening condition to live their life in the way that they should live it, nor in the way that, I believe, they have a right to live it.

It is incredibly important to find creative and innovative ways of providing respite that suit people. That could mean bringing together young people with the same condition, so that they can share their experiences, socialise and, my goodness, go out to the pub together. We should be able to support that. Self-directed support can do a bit of that, but some young people like to have respite together, and we need to work together to find ways to provide that.

CHAS, working alongside Volunteering Matters, has been testing using volunteers with children and families at home. We have specially trained volunteers who go into people's homes and provide practical support, such as making beds, doing some cleaning, making a meal or taking the dog for a walk. One of the important things that they are asked to do is to help siblings with homework, to ensure that they can continue to participate in learning at school and become the wonderful, confident young people that we want and need them to be. There are different ways in which we can offer respite support.

The Convener: Bob Doris would like to come in, but before that—

Dennis Robertson: Convener—

The Convener: You have already been in, Dennis. I am asking those who have not asked a question whether they want to come in. After that, I will return to those who have already asked a question.

As nobody else wants to come in, we will have Bob Doris and then Dennis Robertson.

Bob Doris: Thank you convener—I know that time is against us a little.

Last week, I asked Professor Clark about the opportunities that the Carers (Scotland) Bill presents, and the issue has come up a bit today. We hope that, ultimately, a huge number of people will come into the system and will get carer assessments and young carer statements. There will eventually be guidance on how those are set out and done consistently, and on quality and training. Is there an opportunity, during the preparation of the young carer statement and the carer assessment, to find out whether the person doing the assessment or preparing the statement believes that the carer is or is likely in the near future to be providing a palliative intervention on behalf of the family member or loved one? If so, is that an opportunity to start to collect more of the data as consistently as possible and in a structured fashion?

I will sneak in a little second question here. We have mentioned the palliative care register. This is to do with my lack of knowledge, but I am not sure how people get on that register. That seems a really obvious question. Could one feed into the other?

The Convener: Could we have quick responses to that, please?

Richard Meade: As you know, in our submission on the Carers (Scotland) Bill we have asked for people who are caring for somebody with a terminal illness to have their care plans fast tracked. If that goes ahead and is part of the bill, it should, we hope, give an opportunity for whoever is filling in the plan to ask the carer what kind of care the person they are caring for needs and whether they are on the palliative care register. There is a really good opportunity there.

Another point that we have made in relation to the Carers (Scotland) Bill is that there should be a greater role for GPs in identifying carers. That is a good place to pick up someone who is in palliative care, so there is potentially some crossover. As I understand it, GPs maintain the palliative care register; they admit people on to the register. There is definitely an opportunity there.

The Convener: What qualifies people to go on the register?

Richard Meade: I think that it is the GP's decision, based on the diagnosis, but others might correct me on that.

Trisha Hatt: Initially, all patients with a cancer diagnosis went on the palliative care register, but—

The Convener: So the register is limited to cancer.

Trisha Hatt: No, it is not, but there is a need for more people with other diagnoses to be added to the register. People with a cancer diagnosis often have multiple comorbidities: they may die as a result not of their cancer but of other conditions.

The Convener: We will make some inquiries on that.

Trisha Hatt: Richard Meade makes a great point: the carer assessment would be a fantastic way to collect that information. If we get a sudden surge of people with carer assessments, we will need to be prepared to be able to support them.

Amy Dalrymple: If you asked a carer whether or not they were providing a palliative care service, I am not sure that they would be able to tell you. The system needs to be a bit cleverer than that. The person doing the assessment must be able to assess whether the care that is being provided is of a palliative nature or not.

The proposed carer support plan and the assessment of personal care must be joined up in order to plan which future services will be required under both.

Dennis Robertson: I have a brief supplementary on Trisha Hatt's point about comorbidities. I am a bit worried that we are moving into silos in talking about dementia, cancer and so on. A lot of people, perhaps just as a result of the ageing process, have sensory or mobility problems. They may have acquired arthritis, or they may have heart disease or be experiencing the effects of a stroke. I understand that other conditions exacerbate illness, but what becomes the principal condition for which we are offering care? Is it the heart disease, the dementia, the cancer or the stroke?

Maria McGill: It is the person and their need. First and foremost, we need to ask what the person and their family needs in order to cope with a series of conditions that they may experience over a number of days, weeks, months or even years.

Trisha Hatt: I absolutely agree. People need specialist input for their specific conditions, but we need to look holistically at the person and their extended family in order to address their needs in a comprehensive and co-ordinated way.

Amy Dalrymple: At Alzheimer Scotland, we are concerned when someone's dementia impacts on their experience of or access to care. We are trying to overcome the barriers that dementia currently creates, but—as I said earlier—we are not interested only in that aspect.

There are people who die of their dementia, and there are many others who die with their dementia, with the dementia having had a significant impact on their experience. I could give you statistics on that, but time is short.

It is important that we look not only at the person but at how the different conditions impact on each other. If the primary condition is physical, such as COPD, the psychological effects of dementia will have an impact. It is very important that each condition is looked at and that we bring together the particular specialised inputs that are required for each condition so that people can access them. We need to ensure that nobody is prevented from accessing the specialist input that they require for one condition—dementia, for example—just because they have another condition.

The issue is not silos, but the need to ensure access and bring everything together, and to recognise that care is not just about dealing with one condition that someone may have.

The Convener: I have a quick question on funding, following on from the aspirational talk about how we would like the world to be.

The written submission from CHAS says that the NHS boards and local authorities will jointly meet 25 per cent of its funding. In a previous meeting of the committee, we received some evidence that around 13.5 per cent of the total cost of NHS funding for CHAS is administered through NHS Tayside. In that evidence session, the health board's interim director of finance, Lindsay Bedford, told us that there was a commitment to revisit the baseline and confirm the agreement of hospice running costs. Has that happened yet?

Maria McGill: Thank you for providing me with the opportunity to discuss this matter. I am sure that there is a willingness on the part of NHS Tayside to meet us—a meeting was planned but, unfortunately, we had to reschedule it. We hope to meet NHS Tayside to discuss the baseline before the end of October. However, that discussion concerns the 25 per cent figure. As you will know from my submission, there is what I would call an anomaly between the funding of children's hospice services and the funding of adult hospice services. My ambition in my early discussions with the Scottish Government is to achieve 50 per cent funding of agreed hospice costs, which I am sure that the committee will support.

The Convener: We will broaden out the discussion to cover that. We tried to establish what level of support there was for the hospices but, to put it politely, the response of the health boards with regard to adult hospices was inadequate. Does anyone have a comment to make on that?

Amy Dalrymple: For us, the issue is not to do with hospice funding; it is about people getting charged for care. Because care tends to happen much more in the social sector, the discussion is much more about the issues around how health and social care funding join up. Those are the biggest funding issues that I suggest the committee could think about further.

Richard Meade: Funding arrangements for adult hospices are set out in a chief executive letter, and the figure is supposed to be 50 per cent.

While my microphone is on, I should say that all the evidence suggests that investment in palliative care services can be completely offset by the savings that are made in acute services, and that you can end up in a situation in which most people can be cared for at home, which would be their choice, and the NHS is saving money.

The Convener: We attempted to get information on the 50 per cent target but the information that we received was inadequate. Do you have any information on whether that target is being met?

Richard Meade: I would have to check.

The Convener: There are no further questions. I thank everyone for their attendance and for their written evidence, which will be helpful to us. We know that you will be watching us carefully in the coming weeks.

12:12

Meeting continued in private until 12:42.

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