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22 June 2023

Dear Minister

# Health, Social Care and Sport Committee: Complex Mesh Surgical Service

- 1. I am writing to you further to the evidence we took on the Complex Mesh Surgical Service (CMSS) during Committee meetings on 2 and 16 May 2023.
- 2. The Committee's current scrutiny of the CMSS follows its previous scrutiny of the Transvaginal Mesh Removal (Cost Reimbursement) (Scotland) Bill, which became an Act on 3 March 2022. During scrutiny of that Bill, the Committee spoke to and heard from women affected by transvaginal mesh. Following passage of the Bill, the Committee agreed to undertake specific follow-up scrutiny of the CMSS to assess how well it is operating and to consider areas for ongoing improvement.
- As part of the initial phase of the Committee's current scrutiny, and informed by previous engagement with affected women, the Committee launched a detailed survey to ask women about their experiences of the CMSS: <u>Experiences of the Complex</u> <u>Mesh Surgical Service - Scottish Parliament - Citizen Space</u>. The Committee received 75 responses and published an anonymised summary of those responses here: <u>CMSS Call for Views Responses</u>.
- 4. The Committee's primary purpose in carrying out its scrutiny of the CMSS has been to highlight the issues raised through this consultation process to those responsible for delivering the service and to explore what is being done and what further can be done in the future to improve the Service so it properly meets the needs of patients.

5. On <u>2 May 2023</u>, we took evidence from the following witnesses:

Witness	Job title and organisation	Relevance
Dr Alan	Chief of Medicine for Women	Overall lead for the CMSS within
Mathers	and Children's Services, NHS	NHS Greater Glasgow and Clyde
	Greater Glasgow and Clyde	
Terry O'Kelly	Senior Medical Advisor,	Scottish Government clinical lead
	Scottish Government	for the CMSS
Dr Anna	Medical Director, Procurement	NHS NSS are the commissioners
Lamont	Commissioning and Facilities,	of the CMSS on behalf of NHS
	NHS National Services	Scotland and commission this
	Scotland (NHS NSS)	service from NHS Greater
		Glasgow and Clyde
Dr Wael Agur	Lead Urogynaecologist, NHS	Local clinician in NHS Ayrshire
	Ayrshire and Arran	and Arran, and member of the
		Scottish Government's
		transvaginal mesh short life
		working group

6. On <u>16 May 2023</u>, we took evidence from you as the Minister for Public Health and Women's Health with responsibilities including mesh and from Greig Chalmers, Head of the Chief Medical Officer's Policy Division, Scottish Government.

### Overarching concerns

- 7. The Committee has been concerned to receive evidence that some women affected by transvaginal mesh do not feel that they have received the comprehensive, co-ordinated, person-centred care they need.
- 8. While the CMSS reports positive feedback from women who have undergone surgery via the Service, there is another cohort of women who have told the Committee they are experiencing barriers to accessing holistic care and support.
- 9. It is widely accepted that complications associated with transvaginal mesh have been complex and traumatising. The Committee has received evidence that these women feel they have been ignored, have not experienced the compassion, choice and control they should be entitled to expect from Scotland's healthcare system, feel disempowered and, as a consequence of these experiences, no longer trust the NHS.
- 10. In July 2020, the Scottish Government announced a national mesh removal service which would provide a clear, single national pathway for treatment. From the evidence it has received, the Committee has concluded that the pathway to all forms of treatment under the service, both surgical and non-surgical, is unclear.
- 11. The nature and purpose of the service does not appear to have been adequately communicated to affected women. Because it operates according to a medical model, the Committee is concerned that the CMSS does not provide the holistic, long-term wraparound support many women feel they need and that, in the Committee's view, they should be entitled to expect.

- 12. Further, the oral evidence the Committee has recently taken demonstrates a lack of urgency from both the CMSS and the Scottish Government in addressing the significant issues many women are encountering when using the service. This situation is particularly regrettable given the ongoing trauma these particular women will have already faced as a result of mesh-related complications.
- 13. Without intervention, the Committee is concerned that a service that was set up to rectify complications associated with transvaginal mesh could further exacerbate women's trauma. The Committee is therefore seeking reassurance that the Scottish Government will take the requisite urgent action needed to address the concerns and recommendations set out in this letter.

### **Referral pathways**

- 14. The 2021 Health and Social Care Alliance (The ALLIANCE) report <u>My Path, My Health, My Life Learning from the experiences of women to plan future mesh services</u>, requested by the Scottish Government, sets out key findings from extensive independent engagement with mesh affected women. One of the recommendations in this report is that there should be clear pathways from referral to follow-up for mesh removal.
- 15. From the evidence, there appears to be confusion and misunderstanding of referral processes and pathways, and potential for considerable variation between different NHS boards and between individual health practitioners making a referral.
- 16. The women who responded to the Committee's survey describe experiences of lengthy waiting, of being referred multiple times before ultimately being seen by local specialists instead of the CMSS, or of not being listened to or referred at all. They describe a service that:
  - has no streamlined, consistent referral pathway with considerable variation between health boards, and
  - has continuity issues where problems can start in primary care, because of a lack of knowledge or understanding, and where problems can arise in secondary care due to a lack of knowledge regarding the referral process. This can potentially result in misdiagnosis and no onward referral.
- 17. According to the NHS Greater Glasgow and Clyde website, the <u>National Mesh</u> <u>Removal Referral Pathway</u> states that women should expect to be referred to the CMSS by a urogynaecologist in their local NHS board.
- 18. At its evidence session on 2 May, the Committee heard that there was still some confusion about referral pathways. Dr Wael Agur, lead urogynaecologist at NHS Ayrshire and Arran, suggested that direct GP referral was possible:

"Ideally, they should first go through the local specialist centre in the local health board that is responsible for the patients, and then to the national centre. However, it is my understanding that there are direct referrals from GPs straight to the national centre".

19. Contrary to this view, Dr Alan Mathers, chief of medicine for women and children's services at NHS Greater Glasgow and Clyde said: "the mesh centre does not now

take direct referrals from GPs", suggesting a recent change to protocol. The Committee is unsure how well this change has been communicated to NHS boards and potential referrers. Dr Mathers went on to explain that patients "are referred by local secondary care using the electronic form that we have insisted on since October 2022".

20. The Committee heard evidence that women's experience of referral can vary depending on their health board/who referred them. Acknowledging this variation, Dr Lamont from NHS NSS stressed:

"It is critical that we acknowledge the difficulties that they have experienced and that we look at the pathway variations between individual boards, the lack of cohesion in referrals and the lack of information around GPs and local specialists that we have heard about".

- 21. The NHS Greater Glasgow and Clyde website sets out the <u>referral process</u> for women as follows:
  - The consultant will refer the patient using the agreed Multidisciplinary Team (MDT) referral form.
  - The GGC MDT will discuss the patient, review all the information provided by the local urogynecologist and recommend a treatment plan.
  - The patient will then be contacted by both the psychology service and the clinical nurse specialist for support and information regarding what to expect at their forthcoming clinic appointment.
  - The patient will attend the clinic and meet the team.
  - They will discuss the proposed treatment plan and any surgical options available to them.
- 22. Following an initial appointment at the CMSS, there appears to be a lack of clarity around the process for onward referral from the CMSS to one of the private providers or to one of the nine NHS England specialist services. The clarity of this process is crucial for women who have lost trust in the NHS in Scotland. The latter option, of referral to one of the NHS England services is not made clear on the website/pathway.
- 23. Dr Lamont reported that the CMSS multi-disciplinary team (MDT) will "work with the women to understand what their preference is". However, she went on to state: "The initial decision around referral is with the MDT from Greater Glasgow and Clyde."
- 24. Mr Terry O'Kelly, senior medical adviser to the Scottish Government, emphasised the importance that women are "supported and empowered to make decisions about their treatment". However, contrary to this view, the NHS Greater Glasgow and Clyde website suggests that decision-making for onward referral rests with the MDT:

"Your case will be discussed at our complex mesh MDT and the outcome will be relayed to you by one of the surgical team members and further appointment/s will be arranged."

25. In your follow up letter of 5 June, about referral processes, you make reference to the National Mesh Removal Referral Pathway. However, this document is unclear on how

the decision for treatment will be made with the flowchart supplied seeming to indicate that this is based on patient choice:



26. When giving evidence to the Committee, Dr Lamont provided a clear description of the NHS NSS pathway for onward referral to private treatment and suggested that, once decided, arrangements are quickly made. However, it is important to note that this referral is not direct from the Service, the woman's case first being returned to their local NHS board for financial approval:

"The referral is then passed back to the local specialist service, because the complex mesh surgical team is not able to make that referral itself. It has to come from the women's own health boards. Once the referral is made, it comes to NSS and we will then authorise it and make arrangements."

27. During your evidence on 16 May, you also spoke about mesh accountable officers in NHS boards and their role in joining up the national service with boards, primary care networks and GPs. Greig Chalmers, head of the chief medical officer's policy division at the Scottish Government, further noted:

"We hope that the websites and information leaflets that we put in place are all good and positive, but we come to the issue in the spirit of knowing that we need some improvement and that there are steps still to be taken".

- 28. In your <u>follow up letter of 5 June</u>, you note that referral pathways for mesh removal have been agreed and communicated to mesh accountable officers in all Health Boards.
- 29. During evidence, Mr Chalmers spoke about commissioning arrangements for the CMSS with NHS National Services Scotland and indicated that the current service level agreement is due to end and will be renewed soon. Mr Chalmers further indicated that the renewal of this agreement would provide an opportunity to seek improvements in the Service. The Committee notes in your follow-up letter of 5 June that this is expected to be available during the summer.
- 30. While noting that referral pathways have been agreed and communicated to mesh accountable officers in all NHS Boards, the Committee is concerned that there still appears to be significant confusion about the referral process and that evidence suggests this confusion applies equally to patients being referred and to those practitioners in both primary and secondary care making referrals.

The Committee has also heard evidence that GPs can refer a patient into a local specialist service which then refers the patient into the CMSS, with the potential for multiple referrals to result in miscommunication which could impact negatively on the co-ordination of care.

- 31. To ensure clarity of referral, the Committee recommends that the Scottish Government reviews the referral process to ensure all patient facing referrers are aware of, and follow, the same referral pathways from primary and secondary care when symptoms suggest mesh might be a factor.
- 32. The Committee further recommends that the Scottish Government undertakes a review of the information and support provided to mesh accountable officers to ensure referral information is communicated to all practitioners in patient facing roles. The Committee looks forward to receiving further information from the Scottish Government on how this will be achieved and how it will be monitored.
- 33. The Committee looks forward to receiving details of the new service level agreement in due course and urges the Scottish Government to make full use of the renewal process to implement meaningful improvements to the service for the benefit of patients using it.
- 34. The Committee also recommends that the National Mesh Removal Referral Pathway should set out all available referral options for surgical removal, including the option of referral to one of the nine specialist centres in England.

#### Waiting times

35. In the responses to the Committee's call for views, women describe negative experiences of excessive waiting times for initial referral, for diagnostic testing and between appointments, as well as repeat cancellations:

"It took me more than 3 years to convince my consultant that several of the symptoms I had been experiencing since 2013 are due to the mesh. It was then 13 months from the date he referred me to the CMSS until I had my first appointment, which was in September 2021. At the end of that appointment, a follow up appointment was arranged for July 2022"

"I first attended Glasgow in 2019 then had to wait till December 2022 for my next appointment"

"Fought for over 4yrs to get 1st referral to Glasgow then wanted a second opinion which I waited again months for referral to Edinburgh where surgery was then scheduled for 2021 ..then that was cancelled and was then advised by surgeon she wasn't allowed to operate in Edinburgh so had to be referred back to Glasgow and still waiting to be seen as of yet ..I am wanting surgery out with Glasgow and Edinburgh now as no faith or trust in any of the teams there"

"most of my appointments had been cancelled I waited nearly 2 tears [sic] in between appointments"

36. During the session on 16 May, Committee Members heard evidence that one meshinjured woman, who had written to Members of the Committee in advance of the session, had been waiting 82 weeks for an urgent referral, while at the same time experiencing debilitating pain.

37. In direct response, Mr Chalmers suggested that the CMSS has been improving and waiting times have been reducing:

"Obviously, that period of waiting will have been profoundly distressing and difficult for the individual involved—that would, of course, not be disputed by the Government. In general, however, GG&C is, in its specialist mesh centre, taking steps to reduce waiting times from a position that, as all involved will acknowledge, required improvement. As things have developed and as the service has, we hope, been progressively improved, the gap between referral for surgery at the centre and the surgery itself is getting closer and closer to 12 weeks, as Dr Lamont and Dr Mathers said on 2 May."

38. While acknowledging that waiting times are getting 'closer to 12 weeks', the Committee is concerned that this maximum waiting time target is still a long way from being achieved. On 2 May, Dr Mathers indicated that:

"In 2021-22, the average wait for the service was 72 weeks. We have moved it down to 55 weeks and we expect it to be 47 weeks by June 2023."

39. As highlighted in the <u>Cumberlege review</u><sup>1</sup>, one of the central issues surrounding harmful complications associated with transvaginal mesh was that women did not feel they were believed and felt dismissed by healthcare providers. Alongside other issues, this led to a significant breakdown in trust in the NHS. In bringing forward legislation to reimburse women seeking mesh removal treatment outwith NHS Scotland, the Scottish Government explicitly acknowledged the need for action to address this breakdown in trust. Women have reported that continued delay and long waiting times are further exacerbating their lack of trust in the NHS system and influencing their preferences on where to go for mesh removal:

"I was referred (sic) in November 2021. This service was set up to help woman with mesh complications. However, the timescale to be seen is a long wait. I want to go to Dr Veronikis for removal."

40. During his evidence, Dr Mathers stated:

"As with every other specialty, we are trying to manage quite considerable waiting pressures. However, although I am still very uncomfortable at the length of time that people are having to wait I think that we have a good news story in that, as you will see from the data that we have presented, the waiting time has been going down steadily, and we expect it to have reduced by a further eight weeks by the summer."

<sup>&</sup>lt;sup>1</sup> <u>First Do No Harm: The report of the Independent Medicines and Medical Devices Safety Review.</u> The purpose of this review was to examine how the healthcare system in England responds to reports about harmful side effects from medicines and medical devices and to consider how to respond to them more quickly and effectively in the future.

- 41. During your evidence, you highlighted plans to introduce a "waiting well plan<sup>2</sup>" to improve people's experiences across the whole healthcare system and support patients while they are waiting.
- 42. The Committee does not believe long waiting times for initial referral to the CMSS, and between appointments, are appropriate given how long some women have been experiencing side effects related to transvaginal mesh. The Committee is of the view that further work is needed to reduce waiting times for the service and to prioritise mesh removal surgery within elective surgery.
- 43. The Committee is concerned that there may be a disconnect between local systems and the CMSS. The Committee recommends that the Scottish Government develops national guidance for effectively managing the symptoms, and co-ordinating any required testing, of women affected by mesh while they are waiting for referral to and treatment by the CMSS.
- 44. The Committee further requests an update from the Scottish Government on progress towards implementing the 'Waiting Well framework' to support people waiting for referral and treatment.

## **Communication and information**

- 45. Women responding to the Committee's call for views also reported inconsistent communication from the CMSS further compounding their feelings of diminished trust in the NHS.
- 46. During evidence, Dr Lamont was clear that:

"The responsibility for communication and care rests with the women's own health boards."

- 47. The ALLIANCE's 2021 report highlighted the experiences of women reporting challenges around communication between their health board and the then national service and recommended that "communication skills are included in the development of the new service".
- 48. However, some women told the Committee they found it hard to make contact with the CMSS or with someone in their own health board if they needed questions answered or were seeking specific support. This was particularly the case if they were seeking treatment outwith the CMSS. Others reported poor communication between appointments or while waiting to hear the outcome of an MDT decision:

"No contacts for service. No email address, no telephone no, no liaison person"

"I have attended the Glasgow Mesh clinic but am still waiting to hear back from them regarding the way forward. I was given a choice of 3 options at the clinic, but these were to be considered and confirmed by their mdt. One of the 3 options was "to do nothing" but that really isn't an option at all is it?"

<sup>&</sup>lt;sup>2</sup> The Scottish Government's <u>*Health and social care: winter resilience overview 2022 to 2023,*</u> refers to developing a 'Waiting Well framework' to support people as they wait for treatment.

49. During evidence to the committee on 2 May, Mr O'Kelly acknowledged that communication and information could be improved around the CMSS. On 16 May, Committee Members expressed concerns that the website for the CMSS, which has been running for several years, was significantly lacking in appropriate information, was hard to find and was not hyperlinked to the NHS NSS website. In response to these concerns, you advised on 16 May that:

"[...] it is important to get the website right and to get support for the women who are in this situation right. There is currently a good amount of information on the website, but it could be improved. There is an argument that a lot of the websites could be improved to ensure that people get the right information and support."

50. Committee Members similarly highlighted the absence of a single patient information leaflet, available to women at the point of referral to the service. In a follow-up letter from the CMSS, received on 10 May 2023, the Committee was advised:

"We are developing a patient information leaflet which will be sent to patients on receipt of a referral into the mesh service."

51. You further confirmed on 16 May that such a leaflet was in development:

"There is some advice on the NHS Inform website, but creating pamphlet literature to support women is incredibly important. We have listened to the women in order to ensure that it contains the right information, whether it is about the pathways for the referral system in the NHS Greater Glasgow and Clyde service or the independent service. I am pleased that we have listened to the women and are able to provide them with the information that they have highlighted is needed."

- 52. In your follow up letter of 5 June, you refer to the existing patient information leaflet on the NHS National Services Scotland website, for women considering surgery with independent providers. Your letter also states that, for women choosing to have surgery at the CMSS, information is provided verbally. However, you do not provide any detail on the development of a single patient information leaflet.
- 53. The Committee has received evidence that currently available information about the CMSS is fragmented and only provided to women on a particular surgical pathway, once a decision on treatment has been made. There is no single patient information leaflet to outline all surgical options, and possible nonsurgical options. The Committee is further concerned that women referred to the CMSS only receive information verbally, giving them little to refer back to and consider while waiting for their appointment, following an initial phone call. Providing such information in writing in the form of a leaflet would give women a much fuller understanding of potential options for surgery as well as alternative pathways should surgery not be appropriate in their circumstances. The Committee believes that providing this information in writing will help minimise confusion and provide clarity to women about what support they can expect to receive from the CMSS and local NHS boards.
- 54. The Committee calls on the Scottish Government to make provision for a single patient information leaflet to:

- enable women to make an informed choice around options for surgical and non-surgical treatment,
- set out potential risks and benefits of the different clinical options,
- set out clearly what support they can expect to receive depending which option they choose,
- set out where and how they can expect to receive support,
- provide details of contact arrangements for those seeking further advice and support.
- 55. While noting that work has recently taken place to improve the website, the Committee has concerns around why this has taken so long.
- 56. The Committee calls on the Scottish Government to:
  - ensure the CMSS, NHS Greater and Clyde and NHS National Services Scotland websites are fully updated, hyperlinked and search engine optimised to ensure women can access the information they need,
  - a single patient information leaflet is disseminated to all local NHS board urogynaecology departments and made publicly available and easily accessible online.
- 57. The Committee further calls on the Scottish Government, in responding to this letter, to set out a clear timetable for implementation of these recommendations to be completed.

#### Holistic support

- 58. The Committee has heard evidence of the need for an integrated system that provides holistic support to women and effectively joins up the different parts of the healthcare system. Accounts from women have highlighted that the experience of the current system is fractured, with no central point of contact, support, or co-ordination.
- 59. During evidence, the Committee repeatedly heard claims that the CMSS is intended to be a holistic service offering surgical options from a variety of providers coupled with localised support in primary and secondary care within each NHS board area.
- 60. Dr Mathers noted:

"The centre attempts to deliver a holistic approach to a wide-ranging problem, and surgery is not always the offered or preferred solution to it."

Mr O'Kelly further noted that:

"The service was developed with a holistic foundation, which will be important as we go forward [...] patients will need non-surgical care and other interventions in the future".

61. The Committee heard during oral evidence that provisions in local NHS boards are intended to be in place to support women throughout all stages, from referral to post-operative support. Dr Mathers suggested there are provisions for women to receive local support in their NHS board for "pain management, psychological issues and

issues requiring physiotherapy" while waiting to be seen at the CMSS. He further argued that those "who elect not to have surgery are not left bereft of care". He added:

"A GG and C patient might see a urogynaecologist in the mesh centre but, if they elect not to have surgery, they can still be referred to a urogynaecologist sub-specialist in the service. The same would be the case for someone coming from Lothian—they would go back to a specialist in that area, because as Dr Lamont said, it is not just about pain; some women will have continence issues, recurrent urinary tract infections and things that will require on-going specialist care."

- 62. Responses to the Committee's call for views indicated a lack of clarity for women about the aftercare they would receive if referred onward for private treatment. Women reported feeling that they had been dismissed from the CMSS at that point.
- 63. In your follow-up letter of 5 June, you set out that the "specialist service in Glasgow is holistic in nature", providing detail that, as part of the CMSS, access to physiotherapy, pharmacy, pain management, mental health and specialist nurses is made available to women following initial referral within the Service. You then outline the process for long-term care to be provided by the patient's local NHS Board.
- 64. While it may be clear to Scottish Government and those involved with delivery of the CMSS that a holistic service is in place, it is clear from women's experiences that they do not feel holistically supported. Responses to the Committee's survey showed that women continue to feel let down, experience prolonged and continued anxiety and disappointment, and feel they are not getting the support they need.
- 65. Dr Agur expressed a view that this disconnect, and uncertainty over what the Service does and does not deliver, could be a result of miscommunication and poor expectation management:

"Whether that holistic service is delivered in the mesh service or in the local health board, that needs to be communicated very clearly to the women, so that they do not feed back in a subsequent survey that there are still concerns about the identity of the service. That could come in the mesh centre information leaflet or perhaps in the information leaflet that we provide locally in the hospital. It is about a holistic service, and surgery is just part of that".

66. Dr Agur further suggested during evidence that the only communication between local specialists and the Service was via the electronic referral form. However, it wasn't completely clear from this discussion whether, following referral to the Service, there is ongoing follow-up with local clinicians and onward co-ordination of non-surgical support such as pain management, psychological support and physiotherapy. Dr Agur also suggested this form was inadequate as the only means for local specialists, with detailed knowledge of the women concerned, to connect with and communicate with the service:

"There are things that I can communicate to a clinician colleague that the electronic form will not communicate."

67. Oral evidence to the Committee suggests there is a growing recognition that a more flexible and responsive service might be required. In connection with this, one Member of the Committee spoke about exploring setting up the equivalent of a

'Maggie's centre<sup>3</sup>' or a 'one-stop shop' for people who have suffered mesh related injuries.

- 68. The ALLIANCE's 2021 report recommended the following should be put in place to support women:
  - "Provide seamless transition to follow up locally through Clinical Nurse Specialists and/or Link Workers based in the national service to support women in a variety of ways including signposting and providing continuity transitions of care".
  - "Develop a multi-disciplinary holistic approach for women who live with complications of mesh insertion and mesh removal".
  - "Form a facilitated national peer support group for women with complications of mesh or mesh removal and support in their self-management".
- 69. During the Committee meeting on 16 May, the Committee explored the need to establish formal mechanisms for the provision of peer support for women affected by mesh, following examples of best practice in other countries.
- 70. The Committee has concerns that:
  - women affected my transvaginal mesh are not aware of the full range of support available to them,
  - there is a lack of clarity about the distinction between those services offered by the CMSS and those offered locally, and
  - there is a lack of clarity for women around how they should go about navigating access to that support.
- 71. The Committee further believes that women affected by transvaginal mesh should be entitled to receive effectively coordinated, seamless, person-centred and trauma-informed ongoing care. To meet this need, the Committee suggests that the Scottish Government should consider if developing an integrated 'onestop shop' might be appropriate to support people who have had mesh related injuries.
- 72. The Committee further recommends that formal peer support mechanisms for women affected by transvaginal mesh should be developed
- 73. The Committee further considers it crucial for the Scottish Government to undertake further public education and awareness raising to manage expectations around what support women can expect to receive from the CMSS, from local NHS boards and from GPs.

# The role of GPs and clinicians

74. During its scrutiny of the Transvaginal Mesh Removal (Cost Reimbursement) (Scotland) Bill, the Committee heard evidence that GPs have a critical role to play in identifying and establishing issues with mesh.

<sup>&</sup>lt;sup>3</sup> Maggie's centres are a network of drop-in centres, which aim to help anyone who has been affected by cancer. They are not intended as a replacement for conventional cancer therapy, but as a caring environment that can provide support, information and practical advice.

- 75. Women who are aware that their problems derive from primary mesh surgery or have had mesh removed privately are still reporting that their experience with some GPs can be less than supportive. The Committee has heard that GPs could potentially prevent referral to secondary care specialists if they are unaware of the range of symptoms exposure to mesh can lead to.
- 76. Some women have developed symptoms from mesh much more recently and the Committee notes there is a particular need to raise awareness of the CMSS for these women so they are in a position to be able to access the Service. However, Members have also heard evidence of cases where neither the affected woman nor their GP are aware that mesh has been inserted, and, particularly in the case of GPs, this may be because the information is not present in notes they can readily access.
- 77. Dr Agur suggested secondary care specialists who have ready access to a woman's hospital records are likely to be best placed to make the appropriate onward referral. He said:

"Those who have access to the hospital records are clinicians such as me, so I need to know whether the patient who is presenting with problems in relation to mesh has had a mesh device or not. Clinicians in the local hospital or health board are best set to find out that piece of information to support a woman and her GP and to receive the referral when it happens".

78. Dr Agur further emphasised the importance of involving referring clinicians in MDT meetings where decisions were being taken about their patient. He argued that this could improve women's experience by enabling referrers to advocate on their behalf during the decision-making process:

"I can see that there are two steps in the pathway that could be replaced by an inperson meeting, a virtual meeting or an invitation to the local clinician who referred from the local hospital to the national centre to attend that part of the national mesh MDT meeting that discusses their patient. At that meeting, I would be able to present my patient to the team and tell them what sort of treatment the woman had locally and what her wishes are. That interface between secondary care and the national centre would boost patient confidence, and hopefully that will be reflected in the next survey".

79. During evidence, Mr Chalmers spoke about the development of a pelvic floor registry that is currently being piloted in four health boards. He noted:

"That will allow for the recording of all treatments for pelvic organ prolapse and stress urinary incontinence as well as mesh removal procedures. We hope that the registry will be an important development in that area."

80. In your follow-up response to the Committee, you helpfully provide further information on this pilot involving NHS Greater Glasgow and Clyde, NHS Lothian, NHS Tayside and NHS Grampian. You further note that the information held within the Pelvic Floor Registry will not be made routinely available to primary or secondary care but that you also made a commitment that "outcomes related to interventions for stress urinary incontinence and pelvic organ prolapse will come from the registry in due course."

- 81. The Committee is concerned about existing gaps in data related to women who have had mesh implanted and who may be experiencing mesh complications. The Committee also has concerns about the pace at which work is currently being undertaken to identify women who have had mesh inserted, as well as about the traceability of medical devices. The Committee calls on the Scottish Government to provide an update, and associated timeline, for implementation of the Scan for Safety Programme<sup>4</sup> and any UK-wide activity being undertaken to establish a national register.
- 82. The Committee also has concerns around GPs' access to information related to women that have had transvaginal mesh inserted. The Committee calls on the Scottish Government to consider how GPs and referring clinicians can easily and routinely identify mesh affected women.
- 83. The Committee recommends that the Scottish Government puts processes in place, such as a single patient record, which will enable GPs and local clinicians to access information that links in with pre-existing data platforms and ensure they have access to up-to-date information. The Committee calls on the Scottish Government, in responding to this letter, to provide an update on work and latest anticipated timescales around the establishment of a single patient record and data platform. Pending the introduction of a single patient record, the Committee asks the Scottish Government to provide detail of interim arrangements it will undertake to ensure appropriate continuation and coordination of care.
- 84. The Committee is of the view that current processes for communication between local services and the CMSS MDT can be improved through better developed and more direct communication between local specialists and the CMSS MDT, and that this would help to ensure better continuity of care. The Committee calls on the Scottish Government to oversee the establishment of a comprehensive communication pathway between local and national specialists to ensure each woman's specific medical history and circumstances are fully understood and considered as part of the decision-making process.

### Specialist training in treating mesh complications

85. Some of the responses to the Committee's call for views expressed a lack of faith and trust in the CMSS to carry out mesh removal surgery safely and successfully:

"I wasn't supported at all I asked how many successful full removals was carried out in Glasgow mesh centre & my question got twisted to me about how many were performed in America/ Bristol."

"Poorly so far. Information is everything and although the 2 consultants I saw claim to be experts in mesh removal and told me they have done "lots" of removals of my type of mesh, pinning them down on factual accurate numbers and outcomes proved impossible while at the clinic."

<sup>&</sup>lt;sup>4</sup> The NHS National Services Scotland website states the Scan for Safety Programme is intended improves the traceability of medical devices through point of care scanning and digital data capture: <u>About the Scan for</u> <u>Safety programme | National Services Scotland (nhs.scot)</u>

- 86. The ALLIANCE's 2021 report highlighted the widespread view of those women involved that being able to have trust in professionals is of paramount importance. At that time, women were looking for assurances that any surgeon operating on them had a clear and proven track record of successfully removing transvaginal mesh. Among the report's conclusions was a recommendation that there should be a system for demonstrating the professional competence of surgeons who undertake mesh removal operations.
- 87. The Cumberlege review also recognised the need for specialist mesh removal centres and recommended that surgeons undertaking complex mesh surgery should be credentialed.
- 88. During evidence, Mr O'Kelly spoke about a <u>curriculum and framework published by</u> <u>the Royal College of Obstetricians and Gynaecologists for specialist training in mesh</u> <u>complications</u>. The Committee understands this will provide the basis for training and credentialing surgeons treating women experiencing mesh complications. Mr O'Kelly noted it would be "really important" to benchmark clinicians in Scotland against that curriculum and framework. Dr Lamont further noted:

"Primarily, the mechanism towards that benchmarking is credentialing, which is the route that we are going down. It will take time because it has not been done specifically in Scotland. However, there is a commitment to that credentialing from the team within NHS Greater Glasgow and Clyde, which has already progressed and applied for it, with the expectation that all those in NHS Greater Glasgow and Clyde will then qualify for it."

89. The curriculum website sets out the importance of providing specialist training for practitioners working in specialist centres across the UK, the process for doing so and the progress that has been made so far in this area. The <u>mesh purpose statement</u> states:

"This area of clinical practice is new and there are no formal training programs for surgeons worldwide, including the UK... Surgeons have developed their surgical skills and expertise within their own departments to remove mesh implants from the vagina, bladder, urethra and abdominal cavity; often working with their colorectal, plastic surgery, orthopaedic and other colleagues... Within the commissioned centres, there is already a recognised requirement for surgeons with advanced training in urogynaecology (RCOG subspecialty accreditation), urology (special skills training in female, functional and reconstructive urology or colorectal surgery). However, specific and tailored training requirements in mesh implant removal does not form part of the commissioning specification."

- 90. The Committee is encouraged to hear of ongoing work around credentialing but has concerns over the pace of progress, and that training in mesh implant removal does not seem to form part of the role specification provided by the Royal College of Obstetricians and Gynaecologists. The Committee seeks further information from the Scottish Government on plans to ensure women affected can be confident that surgeons within the CMSS are competent in mesh removal.
- 91. The Committee understands a contract for mesh removal surgery was initially concluded with private providers for a period of one year and is due to end in

June 2023. However, NHS NSS has confirmed that work is ongoing to extend the contract for a further year. During evidence, women have reported a lack of confidence in the competence of the CMSS to provide mesh removal surgery. Coupled with lengthy waiting times for referral to the CMSS, this leads the Committee to seek assurance from the Scottish Government that options to undergo surgery via an independent provider, or in NHS England where medically appropriate, will continue to be made available.

## Staffing

- 92. During evidence, the Committee learned there is a vacancy for the position of Urogynaecology Specialist Consultant within the CMSS, the post having been vacated in July 2022 and recruitment for a replacement having so far been unsuccessful. The CMSS told the Committee in its <u>communication of 26 April</u>, that the post will be readvertised in May 2023.
- 93. In your follow-up letter of 5 June, you noted that a dedicated Urology resource for the Mesh Service is required. However, you further note that "This post is expected to be advertised and recruited to within next 6 months".
- 94. Throughout the evidence-taking process, the Committee has received communications from women affected by transvaginal mesh expressing concerns around this vacancy. In your follow up letter, you note that, in response to these concerns, "appropriate arrangements have been put in place to ensure the safety and wellbeing of patients".
- 95. The Committee is concerned over the delay in advertising and recruitment for a Urogynaecology Specialist Consultant within the CMSS. The Committee believes that this recruitment should be prioritised and arrangements put in place to give affected women the assurance they need to be able to trust the Service.
- 96. The Committee therefore seeks reassurance from the Scottish Government that the recruitment campaign will be progressed as soon as possible and asks the Scottish Government to provide further detail of the 'appropriate arrangements' that have been put in place in the interim, as referred to in your letter.

### **Prevention for SUI and POP**

- 97. Committee Members have heard evidence of the effects of living with stress urinary incontinence (SUI) and pelvic organ prolapse (POP), as well as the complexity of post-operative complications that may occur even if mesh has been fully or partially removed.
- 98. Members further explored the importance of education and awareness raising around the risks of SUI and POP, and the importance of pelvic floor strength during pregnancy.
- 99. During evidence, you outlined plans to launch a programme of short animations and other forms of information and support on the women's health group website. You further noted that "giving information on different exercises in primary and secondary

schools would be a strong way forward" before committing to discuss the issue and possible solutions with the Minister for Children, Young People and Keeping the Promise.

- 100. Committee Members also raised the recent appointment of the women's health champion and priorities for that role, particularly in relation to both prevention and ongoing support for affected women.
- 101. The Committee notes the further information provided in your follow-up letter of 5 June around support available on continence issues from GPs and on the Women's Health Platform, whereby the intention is to add content to that platform focusing on both prevention and help and advice.
- 102. The Committee calls on the Scottish Government, in responding to this letter, to set out what it is doing to focus on downstream interventions to ensure preventative measures are in place for future generations and women can be empowered and supported to be in control of their own health. The Committee seeks commitments from the Scottish Government that information and advice on prevention are further considered and included within:
  - Education and awareness raising in primary and secondary schools
  - Antenatal guidance, in particular improving the information given to pregnant women on pelvic health and the likelihood of incontinence post-partum.

In conclusion, the Committee intends to continue to take an active interest in the operation of the Complex Mesh Surgical Service and to undertake further scrutiny within this parliamentary session.

The Committee looks forward to receiving a detailed response to the points raised in this letter in due course, and no later than **22 August 2023**.

Yours sincerely,

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Clare Haughey MSP Convener, Health, Social Care and Sport Committee