BSSVD
The British Society for
the Study of Vulval Disease

Standards of Care for patients with Vulval Conditions

CONTENTS

EXECUTIVE SUMMARY

These updated quality standards set out the necessary service framework for the provision of care for patients with vulval conditions. Clinicians, managers and commissioners of specialised services should be guided by the clinical and service standards set out in this document.

All patients are entitled to high-quality care that is clinically effective, safe and delivers an optimal patient outcome. This can be challenging to deliver for patients with complicated or rare vulval conditions, who often require specialist care across disciplines. To ensure that these patients receive the most appropriate care, it is vital that commissioners of services have clear information about what constitutes high-quality care, particularly when this requires multidisciplinary services.

While some patients with vulval conditions are well managed within community and secondary care services (within general dermatology, gynaecology or sexual health clinics), those with more complex conditions may need to be managed within a specialist vulval clinic. Equally, patients with rare or complicated vulval disease may need access to a specialist service in the form of a multi-disciplinary team (MDT) providing cross-specialty expertise.

Currently, there are 95 vulval clinics in the UK registered with the **British Society for the Study of Vulval Disease (BSSVD).** Some operate as single-speciality clinics and others are multidisciplinary. Many are already informally networked with regional allied services. They are frequently oversubscribed and patient pathways are not always clearly delineated between services. This update is designed to support service providers, local commissioners and national specialised commissioning.

The aim is to encourage integrated working, support fragile services, define practice standards and ensure that all patients have equitable access to the high-quality services they need through a ‘hub and spoke’ approach (see Appendix 1).

PRACTICE STANDARDS

STANDARD 1: PRINCIPLES OF CARE FOR PATIENTS WITH VULVAL CONDITIONS

Patients are entitled to expect equitable access to high-quality care provided at a level appropriate to their condition and within an environment that meets their clinical needs and respects their dignity.

STANDARD 2: THE MULTIDISCIPLINARY TEAM AND MODELS OF CARE

The complex and cross-disciplinary nature of many vulval conditions requires care to be delivered by an MDT, networked to provide clear care pathways between each service setting. This 'hub and spoke' model for vulval services focuses on quality of care, training, team working and integrated governance across all providers. The three-tier system places tertiary supra-specialist services as the "hub" and specialist vulval clinics as the "spokes" of the model.

STANDARD 3: APPROPRIATELY TRAINED STAFF

A historical and ongoing lack of training in vulval conditions (across almost all disciplines) makes it particularly important that clinical leads are experienced and competent and that every effort is made to promote and share knowledge and training across the extended network.

STANDARD 4: CLINICAL GOVERNANCE

Clinical governance across a vulval service depends on good, regular communication and analysis of and responsiveness to the data generated by continual assessment of outcomes and patient experience.

STANDARD 5: DISCHARGE, MANAGEMENT PLANS AND FOLLOW-UP CARE

There should be clear management and follow-up pathways for all patients including the use of telehealth or remote appointments if appropriate. There should be a focus on patient self-management and education. Patients should have robust, clear plans if being discharged back to their GP or members of the MDT. These plans should include advice regarding ongoing management, indications and pathways for re-referral, and any ongoing prescribing requirements (particularly for high-cost drugs).

INTRODUCTION

BACKGROUND

The BSSVD is a multidisciplinary professional society dedicated to the care of patients with vulval conditions. In 2021, following a major public engagement exercise, the Government published a vision for its 'Women's Health Strategy'[1]. Many of its future plans to improve women's health map to the BSSVD's priorities – breaking down taboos, improving information and education, gathering evidence and data, improving research, managing long-term conditions and promoting healthy ageing[1].

Genital disease is common and causes significant morbidity[2], with incidence and prevalence figures likely to be underestimated due to perceived stigma and often prolonged self-treatment deterring patients from seeking advice[3]. Vulval lichen sclerosus, an example of one such disease, is thought to affect 0.1% of children and 3% of women over 80[4]. A vulval health survey of over 300 women undertaken in 2015 by the British Association of Dermatologists reported a significant impact on daily living such as walking (38%), urinating (50%) and sleeping (36%), with 84% describing impacted sexual function, 79% reporting it affected personal relationships and with 22% having thoughts of suicide or self-harm. The NHS 2019 plan outlines the need for patients to be provided with more options, better support and joined-up care at the right time in the optimal setting[5], and although it is well recognised that patients with complex vulval conditions are best managed within an MDT[6], it can be difficult to access all levels of care. Delays of up to 10 years have been reported between the onset of symptoms and a definitive diagnosis[7].

In the UK, some patients with vulval conditions attend specialist vulval clinics for care. Over recent years a large number of these clinics have been set up around the UK. According to the BSSVD, there are around 95 such clinics in the UK but provision is geographically patchy (see the BSSVD database of vulval clinics map) and standards variable[8]. Different combinations of consultants work within the clinics from specialities such sexual health, dermatology and gynaecology. Most clinics have been set up by interested clinicians rather than through formal commissioning. Workforce limitations, poor commissioning, lack of succession planning, informal networks and over subscription of services all contribute to inconsistency and fragility of these services.

TACKLING UNMET NEED

There are significant unmet healthcare needs in patients with vulval disease. Currently, access to the correct specialist team is variable depending on the local services. Once seen, there are a number of treatments for complex conditions that are not uniformly available to patients. There is a significant disease burden for some particular patients with inflammatory, premalignant and chronic pain conditions. These patients require a holistic, MDT approach as part of the hub and spoke model.

ENSURING EQUITABLE ACCESS TO CARE

Our standards document will ensure uniformity of access for patients by stratifying care and referral through the hub and spoke model. This will ensure that the correct patient is seen by the correct person at the right time. There will be benefits for disadvantaged groups as we believe there remains an unrecognised disease burden in this cohort. The multidisciplinary approach to care we propose will ensure that the health outcomes of these groups are addressed.

CLINICAL PRACTICE OUTCOME MEASURES

There is not currently a nationally agreed set of clinical practice outcome measures to use during vulval consultations. There are no robustly validated tools for vulval disease. However, the goal of treatment for vulval conditions, regardless of aetiology, is similar: minimise symptoms, optimise daily function and prevent complications (such as scarring and malignancy). In addition, the effect of vulval conditions on mood has been documented; it is not infrequent for patients to have mood disturbance. It is, therefore, good practice to document the following aspects when assessing vulval patients in the outpatient clinic:

- Patient-reported symptoms
- Clinician-reported signs
- Impact on day-to-day function
- Impact on sexual function (if relevant)
- Impact on mood (if relevant)

General tools are available for dermatology life quality (e.g. DQLI, Skindex), overall health (e.g. Sf 36, EQ5D), mood (e.g. HADS, PHQ-9) and sexual function (e.g. FSFI). Clinicians will often use these in their vulval consultations. A recent tool developed by Fischer et al, the VQLI, has not been externally validated but can be considered as an alternative to the DQLI as it is vulval specific. Clinical signs are best documented with clinical photographs although this is not always practical and schematic representations of disease extent/severity are often used. A future goal is to have an agreed clinical practice outcome measure data set to be used in all vulval consultations.

THE AIM OF THESE STANDARDS

The aim of these standards is to support equitable access to high-quality care for people with vulval conditions. If services are delivered to these standards, clinical outcomes for this group of patients should improve greatly.

A NOTE ON THE SCOPE OF THIS DOCUMENT

This document does not cover clinical guidelines as these have been developed by other specialist organisations (see Appendix 4), nor does it cover more generic standards for high-quality care (e.g. information governance).

LEVELS OF SERVICE PROVISION

Patients with vulval disease may be seen within many disciplines. These include but are not limited to general practice, family planning services, psychosexual therapy, incontinence services, specialist physiotherapy, sexual health services, paediatrics, gynaecology, dermatology, oral medicine, colorectal surgery, pain services and colposcopy. For the purpose of the following standards, and for developing networked services and pathways, the provision of care is described at the following levels: (Appendix 1)

Level 0:	Primary care services
Level 1:	Primary care services and community services with an interest in vulval conditions and non-specialised hospital services (e.g., general dermatology, general gynaecology, sexual health services).
Level 2:	**Spokes** – Specialist care usually within a dedicated vulval clinic (dermatology, gynaecology or sexual health), often hospital-based but may also be delivered in the community.
Level 3:	**Hubs** – Tertiary level supra-specialist services e.g., Teaching Hospital and Tertiary Centres including Specialised Cancer Centres.

Demarcations between the different levels of care and provision will vary between regions. There may be more than one hub in a region offering different supra-specialist services. Therefore, it is important for local teams to have the flexibility to adapt their networks to reflect the services within their own localities, keeping quality of care and equity of access for patients as the primary focus. See Appendix 2 for guidance on which conditions may need referral to a vulval service.

STANDARD 1: PRINCIPLES OF CARE FOR A PATIENT WITH A VULVAL CONDITION

Patients are entitled to expect equitable access to high-quality care provided at a level appropriate to their condition and within an environment that meets their clinical needs and respects their dignity.

RECOMMENDATION	DESCRIPTION	RATIONALE
1.1.1 **Ensuring the patient is seen by the right health professional**	Patients who cannot be managed in Level 1 services should be referred for diagnosis, assessment and or management by a clinician with specialised training to deal with their specific problem. Patients should be referred and assessed within national timescales, complying with national targets and meeting NICE guidance.	Not all patients with vulval problems require access to a vulval service. Some can be managed in community or non-specialist hospital services. Appendix 2 offers guidance for clinicians in level 0 or level 1 healthcare settings, on which conditions might warrant referral to a more specialised vulval service.
1.1.2 **Information and support for people with vulval conditions**	All patients should be provided with adequate peer-reviewed patient information on their condition (information specific to their condition type/severity and advice on treatment) that meets the information standard. This may include online resources. They should be directed to relevant patient support groups as necessary. Patients should be given information that reflects any religious, ethnic or cultural needs and takes into account whether they have any physical or learning disability, sight or hearing problem or language difficulty. Services should recognise the importance of language used around patients in need of vulval care and avoid making gendered assumptions. Non-binary people assigned female at birth, trans women and trans men may all need specialist vulval care (depending upon surgical and hormonal treatments)	Patients should be supported throughout their treatment with relevant written information to support compliance and to relieve anxiety and distress associated with their condition. Contact with established patient support groups may be of benefit for informal support, as a source of further patient information and, importantly, in overcoming the isolation that many patients with chronic vulval disease experience.

RECOMMENDATION	DESCRIPTION	RATIONALE
1.1.3 **Vulval clinic facilities**	Level 2 and 3 specialist vulval clinics should have adequate clinical examination rooms with couches and lighting suitable for assessing the vulva and with swabs/specula available as needed. There should be adequate provision for patient privacy with space and facilities for chaperones. There should be access to: • Genital tract infection screening • Outpatient vulval biopsy Within genitourinary medicine settings, microscopy at the hospital visit is preferable. There should be appropriate nursing and secretarial support.	Patients referred with vulval disease often have a high level of anxiety and stress and it is of the utmost importance that there is an appropriate clinical setting in which to take a history and conduct an examination. A vulval biopsy service should be available in the clinic and, ideally, should be performed at the time of the clinic visit. Patients should have appropriate consent and support from a nurse during and after the procedure. Appropriate aftercare support should be provided.
1.1.4 **Medical photography**	Medical photography facilities and storage should be available on site. Where photographs are taken, this should be done only with the patient's informed consent. Clinicians can request patient consent for images to be used later for teaching or publication purposes where appropriate. Patient self-generated images may be viewed during the face-to-face consultation, but current NHS practice does not suggest a formal transfer of such images to the Trust.	Medical photography of vulval disease provides an objective means of recording clinical findings to help establish a diagnosis and monitor treatment and disease control. Although this practice is well developed in dermatology, it is underused in other specialities. Photographs, used with the patient's consent, are extremely valuable in terms of education and research.
1.1.5 **Consultation times**	This will depend on the level of service being provided. A minimum 30-minute consultation for a new patient referred to a Level 2 (spoke) vulval service should be allocated, with at least 15 minutes for a follow-up appointment. More time may be required for complex cases or those at Level 3 (hub). Consideration should be given to changes in practice following the COVID pandemic. Telephone or video consultation for follow-up patients may be appropriate in some circumstances where a clinical examination is not indicated.	Rare or complicated vulval conditions require adequate time for consultation. Due to the COVID pandemic, flexibility in approach should be considered. Networks can agree on pathways for MDT involvement. For example, prior to a face-to-face hub review, prior discussion at the MDT may be of value to optimise clinic time and avoid duplication of patient care.

RECOMMENDATION	DESCRIPTION	RATIONALE
1.1.6 **Using national guidance**	Whenever possible, management of vulval conditions should be in line with national guidance produced by professional bodies (BSSVD, BAD, BASHH, RCOG, ECSVD) and NICE. Guidelines currently exist for lichen sclerosus, lichen planus, psoriasis, eczema, vulval intraepithelial neoplasia, vulvovaginal candidiasis, infections and vulvodynia.	There are national evidence-based guidelines produced by specialist societies on a variety of vulval conditions. These are widely available online – see resources below (Appendix 4)
1.1.7 **Recording clinical data**	Where possible clinical data on patients should be collected for potential research and local/regional audit.	Clinical practice outcome measures are important for clinical governance, audit and research. Photographs, used with the patient's consent, are extremely valuable in terms of education and research.

STANDARD 2: THE MULTIDISCIPLINARY TEAM AND MODELS OF CARE

The complex and cross-disciplinary nature of many vulval conditions requires care to be delivered by an MDT, networked to provide a set of clear care pathways between each service setting. This 'hub and spoke' model for vulval services focuses on quality of care, training, team working and integrated governance across all providers. The three-tier system places tertiary supra-specialist services as the "hub" and specialist vulval clinics as the "spokes" of the model. Level 1 services include community services with an interest in vulval conditions and non-specialised hospital services (e.g. general dermatology, general gynaecology and sexual health).

RECOMMENDATION	DESCRIPTION	RATIONALE
2.1.1 **Specialist services – Level 2 service provision (spokes)** **Generally hospital-based but may be provided in some community settings.**	These services should have networks to enable referral of patients to other key services such as oncology, specialised physiotherapy, psychosexual therapy, continence advisory services and pain management. They should have pathways in place to allow referral to the regional hub (Level 3 service) for those patients with rare or complex disease who need management in a supra-specialist multidisciplinary setting and should be part of the network vulval MDT.	Patients with vulval conditions who are referred from community and general hospital services should be managed by health professionals with expertise in vulval disorders across different specialities. They are usually clinicians who see patients at the first referral visit to specialist secondary care services, usually within a vulval clinic. Core members should be senior health professionals who have experience in the assessment and management of vulval disease. It is recognised that these health professionals may be either medical and/or nursing staff depending on the service configuration.
2.1.2 **Supra-specialist tertiary services – Level 3 service provision (hubs)**	These services should have networks to enable management of patients with rare and complex vulval diseases including those covered under NHS England Specialised Services. Specialised Vulval Services should provide multidisciplinary clinics with clinical leads from gynaecology and dermatology with access to a full range of allied services to support these patients. There should be clear networked pathways between sexual health, pathology, specialist physiotherapy, pain management, continence services, AIN/VIN services, oral medicine, gynaeoncology, paediatric services, clinical psychology and psychosexual therapy. There should be pathways in place to allow discharge and management of patients back to local services (spoke services – Level 2).	Many vulval disorders require input from different disciplines. An MDT vulval service offers patients with complicated or rare disease access to a wider variety of treatment options through multidisciplinary input, increasing levels of appropriate care, and also provides access for patients to trial treatments and research.

RECOMMENDATION	DESCRIPTION	RATIONALE
2.1.3 **MDT Measures**	The regional vulval service should host a virtual MDT of all Level 2 (spoke) services in their region to provide a multidisciplinary network to integrate patient care between the different levels of service (See Appendix 2). A hub MDT vulval service should have the following in place: • Core membership from Dermatology and Gynaecology +/- Sexual Health • Pathways to accept referrals from regional spoke services • Arrangements with local spoke services to guide and plan treatment • A Governance framework (guidelines, SOPs, patient information, audit) • Clear pathways to all allied services (if not part of core service) • A training programme with funding for at least one senior trainee in vulval disease from gynaecology or dermatology (on Vulval ATSM or post CCT fellowship) • A regional education programme for service providers	A team approach is required for the management of complex vulval disease. This also facilitates a strong focus on education and training across specialties involved in patient care. This includes support services from sexual health, pathology, specialist physiotherapy, pain management, continence services, AIN/VIN services, oral medicine, gynaeoncology, paediatric services, clinical psychology and psychosexual therapy. Education and training with succession planning are essential for the stability and sustainability of tertiary vulval services.
2.1.4 **Clinical leadership**	One or two named lead clinicians should be identified to take a formal lead role within the MDT service. Their responsibilities should include: • Overall clinical governance • Ensuring the sustainability of the service • Coordinating clinical meetings	Clinical leadership is fundamental to creating an environment in which clinical effectiveness can flourish.

RECOMMENDATION	DESCRIPTION	RATIONALE
2.1.5 **Teamwork and communication**	Regular MDT meetings should be held to discuss difficult cases. Meetings every one or two months are suggested based on clinical workload. These MDT discussions should also address matters such as service delivery, communication to the patient and GP, clinic set-up, audit and clinical governance.	Many patients with complicated conditions require an MDT approach, which is best facilitated by regular MDT meetings. Clinical records/minutes (as relevant) should be kept for all formal MDT meetings and there should be an agreed distribution list for the minutes.
2.1.6 **Clinical pathways**	Local pathways should be developed between the three tiers of service to help ensure appropriate and equitable access for patients according to need. This should also ensure that Level 2 and Level 3 clinics are not overburdened with referrals that may not require these specialist services. Within the vulval service itself, there should be clear referral pathways to different members of the team when they are not operating as part of a multidisciplinary clinic.	National pathways for vulval disease have, historically, been poorly developed. The development of local pathways between Level 1 and Level 2 services and regional pathways for Level 2 and Level 3 services should work in parallel with established guidelines to provide better outcomes for patients. The MDT may not operate within a single clinic and patients might need to be referred to other members of the team. Some patients will benefit from a package of treatments and may even need to see several members of the team in parallel.

STANDARD 3: APPROPRIATELY TRAINED STAFF

A historical and ongoing lack of training in vulval conditions (across almost all disciplines) makes it particularly important that clinical leads are experienced and competent, and that every effort is made to promote and share knowledge and training across the extended network.

RECOMMENDATION	DESCRIPTION	RATIONALE
3.1.1 **Competence to deliver services and clinical leadership**	Patients with vulval conditions should be seen by health professionals with the appropriate skills and competencies to meet their care needs. Continuing professional development (CPD) is essential for health professionals, and cross-disciplinary working can enhance personal and professional development, leading to better quality care. Employing organisations should, wherever possible, facilitate the attendance of members of the MDT at postgraduate conferences and courses related to vulval disease as appropriate. Health professionals caring for patients with vulval cancer should be accredited to do so and be a part of the local gynaecological cancer network MDT.	Vulval clinics are usually run by senior medical and nursing staff. There is an assumption that medical and nursing staff running vulval clinics/services are competent in the assessment and management of vulval disease. Trainee doctors working within the vulval service should look towards their speciality-specific curriculum to direct their training. Newly appointed consultants may join a vulval service to become a core member, as they will have completed their speciality core curriculum which covers vulval disease. Ideally, however, any individuals appointed to such posts should have evidence to support ongoing interest in vulval disease (e.g., research, audit). For gynaecologists, completion of the Advanced Training Skills Module (ATSM) in vulval disease would be desirable, for dermatologists, the post CCT fellowship in vulval disease is recommended and for nurses completion of the British Dermatology Nurses Group vulval disease competency framework.
3.1.2 **Training for health professionals beyond the core MDT members**	The clinical lead in conjunction with the wider MDT should nurture educational and training support to those health professionals outside the MDT involved with women's health, both in community services and specialist care.	The educational and training requirements of health professionals outside the MDT are unlikely to be met within existing curricula. Training in the assessment and management of vulval conditions is highly variable and, in some cases, non-existent, particularly among GPs, physiotherapists and nurses providing first point of contact care. The wider MDT can facilitate education and training to help improve the diagnosis, management and/or referral of patients with vulval conditions. This can be undertaken through a variety of methods (e.g. clinical attachments to the vulval service and/or attendance at training courses, lectures and workshops).

STANDARD 4: CLINICAL GOVERNANCE

Clinical governance across a vulval service depends on good, regular communication and analysis of and responsiveness to the data generated by continual assessment of outcomes and patient experience.

RECOMMENDATION	DESCRIPTION	RATIONALE
4.1.1 **Clinical governance in practice**	It is essential that clinical governance arrangements are embedded in clinical practice to enable service providers to constantly review and measure themselves in terms of effectiveness, safety and patient experience. This can be achieved through a variety of means such as: • Audit • Notes review • Risk management • Review of complaints • Patient satisfaction surveys Collecting patient-reported experience and outcome measures (PREMs and PROMs) should also be considered as part of clinical governance.	Better outcomes for patients with vulval disease are likely to be achieved if treatment is of a uniformly high standard, consistent and in line with national guidelines. The process of audit, notes review and patient surveys are examples of how this can be assessed (see Appendix 3).
4.1.2 **Patient involvement**	Patients' views about their treatment experience should be sought and considered. These views should be used to inform the delivery, development and continuing governance of all services.	Commissioners and clinicians should embrace the opportunity of drawing upon the knowledge, experience and expertise of patients with vulval conditions. Patients can feed back on existing services using PROMs and PREMs. For the development of new services, patient support groups are a valuable resource. Vulval-specific support groups include Worldwide Lichen Sclerosus Support, the Vulval Pain Society and UK Lichen Planus.

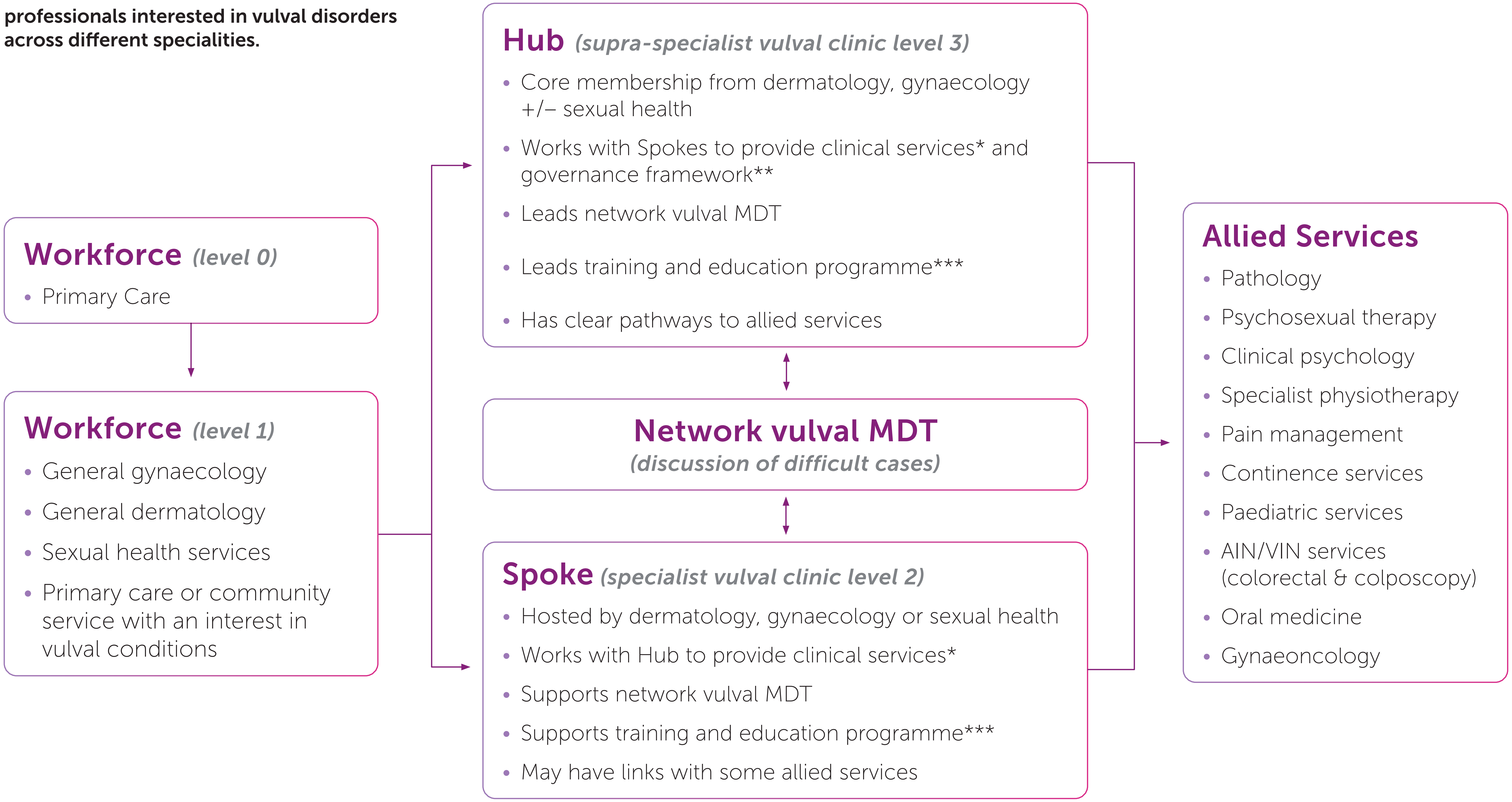
STANDARD 5: DISCHARGE, MANAGEMENT PLANS AND FOLLOW-UP CARE

There should be clear management and follow-up pathways for all patients including the use of face-to-face and virtual appointments. There should be a focus on patient self-management and education. Patients should have robust, clear plans if being discharged back to their GP or members of the MDT. These plans should include advice regarding ongoing management, indications and pathways for re-referral, and any ongoing prescribing requirements (particularly for high-cost drugs).

RECOMMENDATION	DESCRIPTION	RATIONALE
5.1.1 Follow-up	Follow-up pathways should be in place between the three tiers of service to help ensure appropriate and equitable access for patients. The pathway should indicate the nature of follow-up (face-to-face or the option of virtual clinic) and how to gain access back to the service in the event of a complication or concern.	Stratification of clinical follow-up is important. Certain networks will have geographical considerations and limits in terms of capacity that will preclude patients from travelling for 'routine' follow-up appointments. The use of virtual clinics may be appropriate for selected patients.
5.1.2 Discharge from the service back to the GP	When discharging patients back to Level 0 and Level 1 services, clear information should be given to the GP and patient with regards to ongoing management, including how to manage disease flares or complications. There should be clear pathways for clinicians and patients back to the specialised services if required. Consideration should be given to patient-initiated follow-up and advice. If appropriate there needs to be clarity with ongoing prescribing of drugs from tertiary pharmacy services to local/community pharmacies.	Not all patients require long-term Level 2 follow-up and many can be safely discharged to the care of the GP with adequate guidance. Patients should be able to and know that they can regain access to specialised services quickly and easily if required.

APPENDIX 1: A HUB AND SPOKE APPROACH TO VULVAL SERVICES

A vulval service is defined as an MDT of health professionals interested in vulval disorders across different specialities.



Workforce *(level 0)*

- Primary Care

Workforce *(level 1)*

- General gynaecology
- General dermatology
- Sexual health services
- Primary care or community service with an interest in vulval conditions

Hub *(supra-specialist vulval clinic level 3)*

- Core membership from dermatology, gynaecology +/– sexual health
- Works with Spokes to provide clinical services* and governance framework**
- Leads network vulval MDT
- Leads training and education programme***
- Has clear pathways to allied services

Network vulval MDT

(discussion of difficult cases)

Spoke *(specialist vulval clinic level 2)*

- Hosted by dermatology, gynaecology or sexual health
- Works with Hub to provide clinical services*
- Supports network vulval MDT
- Supports training and education programme***
- May have links with some allied services

Allied Services

- Pathology
- Psychosexual therapy
- Clinical psychology
- Specialist physiotherapy
- Pain management
- Continence services
- Paediatric services
- AIN/VIN services (colorectal & colposcopy)
- Oral medicine
- Gynaeoncology

***Clinical services provided**

- Rare disease
- Complications of vulval disease
- Non-responders to treatment
- Co-ordinates care with MDT

****Governance framework**

- Agreed pathways dependent on local services
- Guidelines
- Standard Operating Procedures and meetings
- Audit
- Patient information

*****Training and education programme**

- Service leadership development
- ATSM in vulval disease for gynaecologists
- Vulval dermatology post-CCT Fellowship
- BDNG nurse training package in vulval disease
- Regular educational meetings for service levels 1, 2 & 3

APPENDIX 2: GUIDANCE ON APPROPRIATE LEVELS OF CARE FOR VULVAL CONDITIONS

LEVEL OF CARE	ROLES AND RESPONSIBILITIES	SUGGESTED CONDITIONS
Level 1 services: **Community services with an interest in vulval conditions and non-specialist secondary care (general gynaecology, general dermatology and sexual health).**	Patient assessment (history taking, clinical examination, microbiological swabs +/- biopsy). Treatment for common conditions. Follow-up.	Uncomplicated vulvovaginal infections (e.g. candidiasis), vulval eczema, vulval psoriasis, uncomplicated lichen sclerosus. Follow-up of more complex disease following discharge from Level 2 services.
Level 2 services – spokes: Hospital-based specialist care, usually within a dedicated vulval clinic (dermatology, gynaecology, sexual health). Some services may be provided in community settings.	Patient assessment (history taking, clinical examination, microbiological swabs, +/- biopsy). Treatment for common and uncommon conditions. Follow-up. Referral of certain patients to supra- specialist care (vulval service).	Lichen planus, more complex lichen sclerosus, vulvodynia, unifocal VIN. Complicated infections (i.e., candidiasis resistant to basic treatment).
Level 3 services – hubs: Supra-specialist care (vulval service).	Assessment and management of uncommon and rare vulval disease. Follow-up.	Complex dermatoses (multi-site, erosive or hypertrophic lichen planus, treatment-resistant lichen sclerosus). Multifocal VIN, Paget's disease. Complex genital Crohn's disease. Vulval disease which impacts on conception/obstetric care. Patients with symptoms that do not respond to standard treatment. Rare conditions (e.g., bullous disorders, genital graft versus host disease, complications of gender reassignment surgery or treatment).
Gynaecological cancer team.	Patient assessment and treatment of pre-malignant and malignant vulval disease. Liaison with the extended cancer team.	Vulval cancer, multifocal VIN (all types including Paget's disease).

APPENDIX 3: AUDIT QUESTIONS FOR HUB AND SPOKE SERVICES

AUDIT QUESTIONS FOR SPOKE SERVICES		YES/ NO
1	Do all patients with vulval disease receive their first definitive treatment within 18 weeks of the date of initial referral?	
2	Are patients offered access to a chaperone or invited to bring their own?	
3	Is the department able to carry out the majority of its vulval biopsies at the same time as the patient's clinic visit?	
4	Are all patients offered up-to-date patient information about their diagnosis and management in a format and language appropriate to their needs?	
5	Does the spoke service participate regularly in the regional MDT?	
6	Are patient-reported outcome and experience measures used by the service?	

AUDIT QUESTIONS FOR HUB SERVICES		YES/ NO
1	Does the MDT meeting occur regularly and include all regional spoke services?	
2	Are clear pathways to Spokes and all allied services in place?	
3	Does the hub host a specialised training programme (ATSM or post-CCT fellow post)?	
4	Are national evidence-based guidelines in place (e.g., from NICE and specialist societies)?	
5	Are there clear referral pathways to different members within and across the entire vulval service?	
6	Are regular educational meetings held across the MDT?	
7	Does the service hold or contribute to a vulval service database?	

APPENDIX 4: RESOURCES, PROFESSIONAL SOCIETIES AND STAKEHOLDERS

	DETAILS	SOURCE
British Society for the Study of Vulval Disease	Professional organisation for health professionals interested in vulval disease.	http://www.bssvd.org
Royal College of General Practitioners	Professional organisation for GPs.	https://www.rcgp.org.uk
International Society for the Study of Vulval Disease	Patient information leaflets, and information on international meetings. Registration required.	http://www.issvd.org
British Association of Dermatologists	Contains lichen sclerosus guidelines and has patient information leaflets on lichen sclerosus, lichen planus, vulval skincare, eczema, psoriasis and vulvodynia. Post-CCT Fellowship in vulval disease.	http://www.bad.org.uk https://www.bad.org.uk/library-media/documents/Post CCT vulval disease Curriculum FINAL sept 2020.pdf
European College for the Study of Vulval Disease	The ECSVD was founded in 1996 to promote communication education and research in the field of vulval disease.	http://www.ecsvd.eu
Royal College of Obstetricians and Gynaecologists	Professional organisation for gynaecologists. Advanced Skills Training Module in vulval disease.	http://www.rcog.org.uk https://www.rcog.org.uk/globalassets/documents/careers-and-training/atsms/atsm_vulvaldisease_curriculum.pdf
British Association of Sexual Health and HIV	Professional organisation for GUM physicians.	http://www.bashh.org
British Association of Gynaecological Pathologists	Professional association for pathologists, with newsletters, meetings, networking.	http://www.thebagp.org

British Dermatology Nursing Group	Development of a 'knowledge skills and competency' package in vulval disease.	https://bdng.org.uk https://bdng.org.uk/wp-content/uploads/2020/09/VulvalCompv7-1.pdf
Institute of Psychosexual Medicine	Provides education, training and research in psychosexual medicine.	www.ipm.org.uk
Pelvic Obstetric and Gynaecological Physiotherapy	A professional network of the Chartered Society of Physiotherapy specialising in the pelvic, obstetric, and gynaecological health of women and men.	http://www.thepogp.co.uk
Vulval Pain Society	Support and information for patients with vulvodynia, vestibulodynia & lichen sclerosus. Contains information on workshops for patients, and links to patient support groups.	http://www.vulvalpainsociety.org
National Vulvodynia Association	US non-profit organisation to improve the lives of individuals affected by vulvodynia. Education, networking, support, awareness and advocacy.	http://www.nva.org

STAKEHOLDERS

- BSSVD (British Society for the Study of Vulval Disease)
- British Association of Dermatologists (BAD)
- British Association for Sexual Health and HIV (BASHH)
- Royal College of General Practitioners (RCGP)
- Royal College of Obstetricians and Gynaecologists (RCOG)
- Faculty of Sexual and Reproductive Healthcare (FSRH)
- Pelvic Obstetric and Gynaecological Physiotherapy (POGP)
- British Dermatology Nursing Group (BDNG)
- Vulval Pain Society

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