

Standards of care for women with vulval conditions



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Executive summary

These standards are intended as a reference guide for both commissioners and practitioners as to what constitutes a good-quality service for women with vulval conditions.

All patients are entitled to high-quality care that is clinically effective, safe and delivers an optimal patient outcome. This can be particularly challenging to deliver – and to assess – in the case of patients with complicated or rare vulval conditions, who often require specialist care across disciplines. To ensure 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 most women with vulval conditions are well managed in primary and secondary care, those with rare or complicated conditions generally need to be managed by a multidisciplinary team (MDT). For example, a patient with vulval intraepithelial neoplasia (VIN) may need access to dermatology and plastic surgery; a patient with vulvodynia may need to access both specialist physiotherapy and psychosexual therapy.

Commissioning needs to allow for referral to multiple specialities and should be based on a team approach – with clear clinical leadership – so the patient has access to core and extended-core members of the MDT.

Vulval services are currently frequently oversubscribed. Patients with less complex needs do not need to be referred to a vulval service if their condition can be managed effectively within primary and secondary care.

This executive summary highlights only the key points from each standard.

Standard 1: Principles of care for women with vulval conditions

Women 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 means that any effective vulval service must be based on the MDT approach, creating a virtual network of care between core and non-core team members and a set of clear care pathways, both into the service from generalist care and within and across the service at specialist and supra-specialist levels.

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 both 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 on analysis of and responsiveness to the data generated by continual assessment of outcomes and patient experience.

Standard 5: Patient and public involvement in service development

When setting up or further developing a vulval service it is important to seek input from patients (via PREMs and PROMs and through contacting patient groups) and members of the public whose care could be affected.



Royal College of
General Practitioners

Introduction

The most effective and equitable services for women with vulval conditions provide care at the appropriate level (recognising that many patients are most effectively managed within primary and secondary care) and offer multidisciplinary care across specialities and at supra-specialist level for complicated and rare conditions.

Background

In the UK many women with vulval conditions attend vulval clinics for care. Over recent years a large number of these clinics have been set up around the UK. According to the British Society for the Study of Vulval Diseases (BSSVD), a professional society dedicated to the care of women with vulval conditions, there are around 80 such clinics in the UK.¹

Little is known about the nature of these clinics. Around two-thirds are multidisciplinary with the remainder being single discipline. Different combinations of consultants work within the clinics from specialities such as genitourinary medicine (GUM), dermatology and gynaecology. The level and quality of care provided by these services is not known and to date no standards of care for vulval services have been developed nationally.

The Royal College of Obstetricians and Gynaecologists (RCOG) in its 2008 document Standards for Gynaecology outlined standards for a benign vulval clinic service, which recognised the role of a lead gynaecologist for vulval disease working within an MDT.² To our knowledge these standards have not resulted in an increased number of clinics within the speciality of gynaecology.

The aim of these standards

The Education and Training group of the BSSVD invited other stakeholders (including representatives of patient groups) to help develop standards for the care of women with vulval conditions focusing on a vulval service rather than vulval clinics. A 'vulval service' is defined as an MDT of health professionals interested in vulval disorders across different specialities. See appendix B for guidance on what conditions might warrant referral to a vulval service.

The aim of these standards is to support equitable access to high-quality care for people with vulval conditions. These standards are intended to form a basis for the development of any NICE quality standards for vulval conditions. If services are delivered to these standards, there is every expectation that outcomes for people with vulval conditions will improve.

Levels of care

The British Association of Dermatologists (BAD) published a set of quality standards in 2011 as a guide for service providers and commissioners of dermatology services.³ The BAD standards document recognises that patients should have their care managed at a level appropriate to the severity and complexity of their condition. It categorises the levels of care as follows:

- Self-care (Level 1)
- Generalist care (Level 2) – primary care level
- Specialist care (Level 3) – usually hospital-based care
- Supra-specialist care (Level 4) – hospital-based care.

We propose that a vulval service should be run as a supra-specialist (level 4) service and suggest that many uncomplicated vulval problems can be managed most effectively at levels 2 and 3. There are, however, educational and training issues relating to vulval disease within primary and secondary-level healthcare and a vulval service can improve the quality of care for patients at levels 2 and 3 through a process of education, audit and the development of clinical pathways, as outlined in these standards.

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 A), nor does it cover more generic standards for high-quality care (eg information governance). For the latter we refer the reader to the BAD standards document cited above.³

References

1. Database of vulval clinics www.bssvd.org
2. Royal College of Obstetricians and Gynaecologists (2008): *Standards for gynaecology: Report of a working party*, RCOG Press. (Available at <http://tinyurl.com/bysgmt8>)
3. British Association of Dermatologists (2011): *Quality standards for dermatology: Providing the right care for people with skin conditions*. London: BAD. (Available at <http://tinyurl.com/6butoyz>)

THE STANDARDS



STANDARD 1

Principles of care for a patient with a vulval condition

This standard covers the fundamental tenets of care as they apply to patients with vulval conditions and sets the context in which all the other standards are applied.

1.1 Recommendations

1.1.1 Ensuring the patient is seen by the right health professional

To facilitate quality care, all patients with a vulval condition should be seen by a clinician trained to deal with their specific problem. Generalist (level 2), specialist (level 3) or supra-specialist (level 4) care should be provided according to the individual needs of the patient.

Clear referral pathways to specialist and supra-specialist (levels 3 and 4) services should be in place, operating within the appropriate timescales, complying with national targets and meeting NICE guidance.

Rationale

Not all patients with vulval problems require access to a vulval service. Many can be managed outside the service in primary and secondary-level healthcare. For some patients with chronic conditions (eg lichen sclerosus or vulvodynia), self-management (level 1) may be the most appropriate option. Appendix B offers guidance for clinicians in primary and secondary healthcare on which conditions might warrant referral to a vulval service.

Patients should receive the first definitive treatment for their condition within 18 weeks of the date of initial referral, as required by law in the NHS constitution.¹

Anyone with suspected vulval cancer should be seen within two weeks by specialists who are part of a gynaecological cancer MDT (level 3 or 4).^{1, 2}

1.1.2 Information and support for people with vulval conditions

All patients should be provided with adequate peer-reviewed written patient information on their condition (general information on the condition, information specific to their condition type/severity and advice on treatment) that ideally meets the information standard.³ If appropriate they should be directed to relevant patient support groups as necessary (eg Worldwide Lichen Sclerosus Support and the Vulval Pain Society). Patients should be given relevant 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.

Rationale

Patients should be supported throughout their treatment with relevant written information to ensure compliance and to relieve anxiety and distress associated with their condition. Contact with established patient support groups and networks 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.

1.1.3 Vulval clinic facilities

Vulval clinics that have been set up within a vulval service 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 and space and facilities for chaperones.

There should be access to:

- Genital tract infection screening
- Outpatient vulval biopsy
- Patch testing.

Within GUM settings microscopy at the hospital visit is preferable. There should be appropriate nursing and secretarial back up.

Rationale

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. This should be a 4-6mm punch biopsy carried out under local anaesthesia and suture.

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 and in accordance with the General Medical Council's guidelines.⁴ Clinicians should be encouraged to ask the patient for their consent for images to be used later for teaching or publication purposes where appropriate.

Rationale

Medical photography of vulval disease provides an objective means of recording clinical findings to help establish a diagnosis and monitor treatment. Although this practice is well developed in dermatology, it is likely to be underused in other specialities.

Photographs, used with the patient's consent, are extremely valuable in terms of ongoing education and research into vulval conditions.

1.1.5 Consultation times

Ideally a 30-minute consultation for a new patient referred to the vulval service should be allocated, with 15 minutes for a follow-up appointment.

Rationale

Rare or complicated vulval conditions require adequate time for consultation.

1.1.6 Using national guidance

As far as possible national guidance, as produced by the specialist societies (BSSVD, BAD, BASHH, RCOG) and NICE, should be followed for managing vulval conditions. Guidelines currently exist for lichen sclerosus, lichen planus, dermatitis, vulval intraepithelial neoplasia, vulvovaginal candidiasis and vulvodynia.

Rationale

There are national evidence-based guidelines produced by specialist societies on a variety of vulval conditions. Some of these guidelines are speciality-specific, for example the lichen sclerosus guidance was updated by the BAD in 2010 and guidance on vulvodynia was produced by the BSSVD in 2009.

These and other guidelines, textbooks and training courses are listed in appendix C.

1.1.7 Recording clinical data

Where possible clinical data on patients should be collected for potential research and local/regional audit.

Rationale

Data on vulval disease in the UK is poor and there is no nationally agreed system of collecting such basic information as clinical diagnosis. The establishment of local data collection will help facilitate local/regional audits and research. Also, collection of data on rare conditions such as Paget's disease and erosive lichen planus might be helpful on a national level for case note review, reviewing optimal treatments and facilitating research.

Data should be obtained, recorded, held, altered, retrieved, transferred, destroyed or disclosed in accordance with the Common Law Duty of Confidentiality,⁵ Caldicott Guidance,⁶ the Data Protection Act (1998)⁷ and other national and professional guidelines.

1.2 Implications for commissioning

1.2.1

Services and models of care for people with vulval conditions should be developed with the involvement of a stakeholder commissioning group and should support the local healthcare needs assessment to ensure that no patient is disadvantaged by restriction of access to accurate diagnosis and effective treatment.

1.2.2

All commissioned services should meet national targets in relation to access times and should follow national guidance and, where it exists, all current NICE guidance – and continue to follow it as it is revised and new guidance is published.

1.2.3

All vulval services that are commissioned should include within the service specification an explicit statement relating to requirements for education and training, assessment of competence, ongoing maintenance of skills, and clinical governance arrangements.

1.2.4

Where commissioners are considering value for money, quality (as measured by effectiveness, safety and patient evidence) should be measured against the standards in this document using available tools. This may include patient-recorded experience and outcome measures (PREMs and PROMs).

1.2.5

The facilities at a vulval service must offer adequate privacy for patients and include provision for chaperones to support patients in accessing all NICE-recommended treatments.

1.2.6

A system should be in place to audit treatment provision against national guidelines, including waiting times for treatment and patient experiences and outcomes.

1.3 Key performance indicators

1.3.1

Proportion of vulval biopsies carried at the same time as the clinic visit. (Standard: 90%)

1.3.2

Access to chaperones (standard 100%)

1.3.3

Audit of adherence to national guidelines.

1.3.4

Database collection of patients' diagnoses from vulval service. (Standard: 90%).

1.4 References

1. Department of Health (2012): *The NHS constitution for England (2012 version)*, London: The Stationery Office. Gateway ref. 17278. (Available at <http://tinyurl.com/ckjg5mx>)
2. National Institute for Health and Clinical Excellence (2006): *Guidance on cancer services: Improving outcomes for people with skin tumours including melanoma: the manual*, London: National Institute for Health and Clinical Excellence. (Available at <http://tinyurl.com/a7ycbkm>)
3. See www.theinformationstandard.org
4. See the General Medical Council's guidance on *Making and using visual and audio recordings of patients*. Available at <http://tinyurl.com/a9g953v>
5. Department of Health (2003): *Confidentiality: NHS code of practice*, London: Department of Health. Gateway reference 1656. (Available at <http://tinyurl.com/4wuhz>)
6. Department of Health (2010): *Caldicott Guardian manual 2010*. Gateway reference 14043. (Available at <http://tinyurl.com/3ya4ea6>)
7. The Data Protection Act 1998, London: The Stationery Office. (Available at <http://tinyurl.com/2c26dx8>)

STANDARD 2

The multidisciplinary team and models of care

This standard describes the multidisciplinary team required to look after patients with complicated and rare vulval conditions that cannot adequately be managed within a single speciality. It also covers the interrelationship between care pathways and links to the other services a patient may need.

2.1 Recommendations

2.1.1 The multidisciplinary team (MDT)

Women with complicated and rare vulval conditions should be managed by a vulval service (level 4 care). This is defined as a multidisciplinary team (MDT) of named health professionals interested in vulval disorders across different specialities. It includes core members from:

- Gynaecology
- Dermatology
- Genitourinary medicine (GUM)
- Pathology.

These core members are usually clinicians who see patients at the first referral visit to secondary care, usually within a vulval clinic. Core members should be senior clinicians and have experience in the assessment and management of vulval disease.

The extended-core members of a vulval service should include representation from:

- Nursing
- Psychosexual therapy
- Pain management
- Clinical psychology
- Specialist physiotherapy
- Reconstructive surgery
- Continence advisory service
- Oral physicians
- Colorectal surgeons.

This extended team structure is important in ensuring access to a toolkit of clinical skills (ie sexual therapy for those patients with sexual dysfunction, pain management for those with intractable vulvodynia, colposcopy for those with multifocal intraepithelial neoplasia, and specialist physiotherapy for those with pelvic floor dysfunction). Patch testing should also be available to patients with suspected contact dermatitis and the service should work closely with a histopathologist with a special interest in vulval skin disease.

Clear access and referral paths to gynaecological oncology services are crucial.

The ideal vulval service should comprise a virtual MDT – a multidisciplinary network of channels of communications between the different core and extended-core members.

Rationale

Effective communication is likely to lead to better patient outcomes with more appropriate treatment for complicated and rare vulval disorders.

Many vulval disorders require input from different disciplines. Two retrospective reviews of specialist vulval clinics have shown that 38% of women needed to be seen by more than one specialist from a range including a gynaecologist, dermatologist, colorectal surgeon, genitourinary physician and psychosexual counsellor.^{1, 2} For these women the MDT reduces the risk of incorrect or inadequate treatment, facilitates communication between specialities and in some cases provides a one-stop service for diagnosis, investigation and management. An MDT-type vulval service offers patients with complicated or rare disease access to a wider variety of treatment options, and an increased level of appropriate care, and also provides a cohort of patients suitable for future research.

The core team members would be the initial contact for patients referred into the service. Pathology is considered a core member of the team because a vulval biopsy is the gold standard for diagnosing many vulval conditions. Working together in joint clinics is encouraged but not essential.

We have included the oral physicians as members of the extended core team as some women with lichen planus have both vulval and oral disease. The services of a histopathologist are helpful in difficult cases where the clinicopathological correlation is unclear. The important role of nurses in the service should not be underestimated and we would encourage their role to be developed according to the teams skill mix. Patients with multifocal intraepithelial neoplasia not infrequently have perianal disease and we have included them as non-core members.

Clear cancer referral pathways are vital for patients with suspected gynaecological cancer requiring urgent referral.

2.1.2 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
- Co-ordinating clinical meetings.

In most circumstance the clinical lead/s will be a consultant or associate specialist.

Rationale

Clinical leadership is fundamental to creating an environment in which clinical effectiveness can flourish.

2.1.3 Teamwork and communication

Regular MDT meetings should be held to discuss difficult cases. Meetings every two months are suggested based on clinical workload. These MDT discussions should also address matters such as service delivery, clinic set-up, audit and clinical governance.

Rationale

Many patients with complicated conditions require an MDT approach, which is best facilitated by regular MDT meetings to discuss clinical cases. As well as patient review, regular MDT discussions should also address matters such as service delivery, clinic set-up, audit and clinical governance. These discussions may be part of the MDT clinical meetings or be held on separate occasions. Certain patients may also need to be discussed at the meeting of other MDTs (eg patients with vulval cancer and some patients with VIN, depending on local arrangements).

Clinical records/minutes (as relevant) should be kept for all formal MDT meetings and there should be an agreed distribution list for the minutes. The issue of effective communication with patients' GPs, including provision of regular outpatient clinic letters and any relevant feedback from MDT team clinical meeting discussions, should be a regular part of MDT meetings, and responsibility for these tasks should be given to a named individual as part of any case discussion.

2.1.4 Models of care for women with vulval conditions

Models of care for patients with vulval conditions should be developed to ensure that patients are seen by the right person, in the right place, at the right time and can move readily between the levels of care as necessary..

Rationale

There is a spectrum of vulval conditions crossing many specialities. Patients with vulval conditions may need access to a variety of these different healthcare professionals depending on their individual needs. Whereas some patients can and should be managed in primary healthcare, many require specialist referral if the diagnosis is uncertain or if the patient does not respond to treatment. For some patients receiving specialist care (within the specialities of gynaecology, dermatology or GUM) supra-specialist referral may be required to a vulval service for a multidisciplinary approach combining specialist skills.

Services should be integrated and are best designed by stakeholders based on a local assessment of need and using the commissioning cycle as a framework. Broad stakeholder engagement and enthusiastic clinical engagement is essential for the success of this process.

An integrated vulval service that engages with clinicians in primary health care and specialist care is usually the most efficient model as the vulval clinic is less likely to be overburdened with unnecessary referrals, as is currently the case.¹

Appendix B offers guidance on the appropriate practitioners and levels of care for various vulval conditions.

2.1.5 Clinical pathways

Local pathways should be developed between the vulval service and primary and secondary health care to help ensure that the most appropriate patients are sent to the service.

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.

Rationale

National pathways for vulval disease have, historically, been poorly developed. The development of local pathways between primary/secondary level healthcare and the vulval service should work in parallel with established guidelines to provide better outcomes for patients. Correct and early referral of patients who have not responded to treatment is likely to provide more appropriate treatments, cost savings and potentially better clinical outcomes. This would apply to all levels of care. Also, multidisciplinary and multi-professional working is recognised as key to providing good-quality care for women with complicated vulval problems. The development of clear care pathways between specialists supports optimal clinical care. Local arrangements for referral will vary and some services might involve direct referral from level 2 to 4 care.

The multidisciplinary team is unlikely to work 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. It is important that there are clear referral pathways to different members within and across the vulval service.

2.2 Implications for commissioning

2.2.1

Commissioners should recognise the importance of a team structure and that some patients may require a multidisciplinary approach. Specific services from the core and non-core team members should be commissioned. The value of the non-core members of the team should not be underestimated and providers and commissioners should consider these members an integral part of the service.

2.2.2

Clinical leadership to run the vulval service and delivery of high-quality care should be supported and explicitly commissioned.

2.2.3

Commissioners should consider how to incentivise service providers to ensure close and collaborative working and optimise clinical outcomes.

2.2.4

Commissioners should create and work with a stakeholder-commissioning group to review and develop models of care and links within the service, using the commissioning cycle and following examples from appropriate national guidance documents.⁴

2.2.5

Commissioners should ensure that care pathways are developed that are clear and appropriate to local needs and meet the holistic needs of each patient.

2.3 Key performance indicators

2.3.1

Service includes a full list of the members of the vulval service (core and non-core) including clinical lead/s. (Standard: 100%)

2.3.2

After each of the regular MDT meetings there is a record of minutes, attendance, patients discussed and outcomes agreed. (Standard: 90%)

2.3.3

Development of clear care pathways between primary and secondary level healthcare.

2.3.4

Development of clear care pathways between the core and extended-core members of the team.

2.3.5

Compliance with acknowledged best practice and/or local guidance.

2.3.6

Evidence that a range of integrated services has been developed using consensus guidance.

2.4 References

1. Sullivan AK, Straughair GJ, Marwood RP, Staughton SE, Barton SE. A multidisciplinary vulva clinic: the role of genitourinary medicine. *J Eur Acad Dermatol Venereol* 1999; 13:36–40.
2. Neill SM, Lewis F, Tatnall FM, Cox NH; British Association of Dermatologists. Guidelines for the management of lichen sclerosus. *Br J Dermatol* 2010; 163:672–682. <http://tinyurl.com/b79f2ng>
3. Vulval skin disorders, management (Green-top 58), RCOG <http://tinyurl.com/aqsyu3h>
4. Primary Care Commissioning (formerly NHS Primary Care Contracting) (2008) *Providing care for patients with skin Conditions: Guidance and resources for commissioners*: <http://tinyurl.com/b5x3apt>

STANDARD 3

Appropriately trained staff

It is vital that patients with vulval conditions are seen by healthcare professionals with the appropriate skills and competence to meet their care needs. Those clinicians working as part of the service will include members of the core team (eg hospital-based doctors) and the non-core team (eg psychosexual counsellors, GPs and practice nurses).

3.1 Recommendations

3.1.1 Competence to deliver services and clinical leadership

Individual members of the MDT (see Standard 2 for a full list of the core and non-core team members) are responsible for their own continuing professional development supported by their employing organisation and commissioners. This should be reflected in an individual's knowledge skills framework (KSF). The clinical lead/s for the vulval service are responsible for supporting but not necessarily delivering the ongoing education and training needs of the MDT members.

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.

Rationale

Women with vulval conditions should be seen by health professionals with the appropriate skills and competences to meet their care needs. Continuing professional development (CPD) is essential for health professionals and cross-discipline 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.

Apart from training for senior gynaecology trainees, there is currently no accredited training process for vulval disease in the UK, nor is there likely to be in the foreseeable future. Vulval clinics are usually run by senior medical staff (Consultants or Staff Grade, Associate Specialist and Speciality (SAS) doctors). There is an assumption that medical 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 would have evidence to support an ongoing interest in vulval disease (eg research, audit). For gynaecologists, completion of the Advanced Skills Training Module (ATMS) in vulval disease would be desirable to be a core member of the vulval MDT.

continued:

The training needs and requirements of members of the vulval service remain undocumented but the establishment of vulval services outlined in this document should help clarify future needs.

There is no formal requirement for health professionals to learn about vulval conditions. The Royal College of General Practitioners curriculum has no mention of vulval conditions beyond requiring knowledge of pruritus vulvae. Likewise there are no knowledge, skill or competence requirements for practice nurses on vulval conditions.

Attendance at vulval courses and study days and joining local vulval clinics are ways of addressing deficiencies in knowledge (see Appendix C for further information).

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 primary (Level 2) and specialist (Level 3) care.

Rationale

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 providing first point of contact care and among nurses. The wider MDT can be useful in education and training to help improve the diagnosis, management and/or referral of women with vulval conditions. This can be undertaken through a variety of methods (eg clinical attachments to the vulval service and/or attendance at training courses, lectures and workshops).

3.2 Implications for commissioning

3.2.1

Clinical leadership, provided by the vulval MDT to support the delivery of education, training and governance should be fostered, supported and explicitly commissioned.

3.2.2

All service providers should demonstrate a workforce development and continuity strategy.

3.2.3

Providers of generalist care (Level 2) are likely to have education and training needs in relation to vulval disease management. Appropriate education, training and governance structures should be commissioned to meet national standards and reflect local needs. Outcomes of training should meet the local needs and gaps in the workforce development plan and continuity strategy.

3.3 Key performance indicators

3.3.1

Attendance at CME-approved national vulval meeting, at least on alternate years, by core members of the vulval service. (Standard: 100% attendance)

3.3.2

For extended-core group members, participation in relevant CPD vulval meetings every 3-5 years. (Standard: 100% attendance)

STANDARD 4

Clinical governance

This standard recommends ways to provide the safest and most effective care for women with vulval conditions.

4.1 Recommendations

4.1.1 Clinical governance in practice

It is essential that clinical governance arrangements are embedded in clinical practice to enable services 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.

Rationale

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.

Vulval services should collect and report PREMs and PROMs, as these are measures of how a patient experiences their care pathway. PREMs are measures of a patient's experience; PROMs are measures of a patient's health outcome. Both reports typically take the form of short, self-completed questionnaires usually administered before and after health interventions. They are used to assess the effectiveness of the treatment, care and support provided.

There is also a range of dermatology-specific quality-of-life tools that can be used to measure clinical outcomes, such as the dermatology quality of life index (DLQI) developed at Cardiff University.¹

4.2 Implications for commissioning

4.2.1

Commissioners should ensure that requirements for clinical governance and accountability are explicit in all contracts with providers of vulval services. Stakeholder commissioning groups provide the opportunity to develop these standards.

4.2.2

Commissioners should ensure that audit requirements relating to the management of women with vulval conditions (reflecting local and national guidance) are specific in all contracts and are monitored.

4.3 Key performance indicators

4.3.1

An annual review of clinical outcomes of the cases seen by the vulval service (see appendix E for a list of possible audits).

4.3.2

Audit of referrals and feedback to referrers to reflect care pathways.

4.3.3

Completion of PROMs and PREMs.

4.4 References

See <http://tinyurl.com/b9emh64>

Standard 5

Involving patients and the public in service development

This standard discusses how patients and members of the public can play an integral part in the development and governance of vulval services.

5.1 Recommendations

5.1.1 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.

Rationale

Commissioners and clinicians should embrace the opportunity of drawing upon the knowledge, experience and expertise that women with vulval conditions can bring to the full commissioning cycle. 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, Vulval Pain Society, UK Lichen Planus and the Vulval Health Awareness Campaign.

5.1.2 Public involvement

Public involvement in developing services should be considered. It is essential that public involvement is fully effective and that services meet the needs of neighbourhoods, as outlined in the Equity and excellence: Liberating the NHS white paper.¹

Rationale

As outlined in the NHS constitution,² it is part of a good NHS service to ensure that any new developments, including expansion and decommissioning, go to public consultation to ensure the broadest possible range of opinions and support.

5.1.3 Patient-reported experience and outcome measures (PREMs and PROMs)

Each provider should collect and report patient-reported experience measures (PREMs) and outcome measures (PROMs).³ The data captured should include holistic outcomes and experience of the whole clinical pathway. Measures should include:

- Overall experiences
- Access to services
- Communication
- Interaction with professionals
- Co-ordination of services
- Care and respect
- Privacy and dignity
- Health information
- Involvement in health decisions
- Signposting to relevant voluntary organisations and support groups.

The development of standard frameworks involving women with vulval conditions would support effective and consistent data collection. The information collected should be used to inform service development.

Rationale

PREMs are measures of how a patient experiences their care pathway. PREMs usually include such measures as:

- *Speed of referral*
- *Respect shown to them*
- *Clarity of the care plan*
- *Patient involvement in decision-making*
- *Suitability of the environment in which they are seen*
- *Effectiveness of interdisciplinary communication.*

PROMs are measures of a patient's health. They typically take the form of short, self-completed questionnaires that measure the patient's health status at a single point in time. They are usually administered before and after health interventions and are used to assess the effectiveness of the treatment, care and support provided. It is acknowledged that these questionnaires are generally poorly developed for vulval conditions, but there are some that can be adapted for vulval conditions, such as the dermatology quality of life index (DLQI) developed at Cardiff University.⁴

5.1.4 Priority setting

Effective consultation and input from the local stakeholder commissioning group (see 1.2.1), will enable commissioners to develop clear arrangements for priority setting and to provide evidence both of the need for any low-priority frameworks or treatment exclusions and of the process by which these decisions were reached.

Rationale

Input from all stakeholders means that decisions can be fully informed and the responsibility for these decisions is shared among all the stakeholders.

5.2 Implications for commissioning

5.2.1

Commissioners should develop and support a stakeholder commissioning group that includes patient representation, as outlined in the Primary Care Commissioning document Providing care for patients with skin conditions: Guidance and resources for commissioners.⁵

5.2.2

Commissioners should expect providers to contribute to a patient and public involvement strategy for the local skin health economy. The strategy should include clear feedback mechanisms.

5.2.3

Commissioners and providers should properly consult with the local population, both users and non-users of services, and must take the outcomes of the consultation into account in the development of their local vision for vulval health, and in the monitoring and evaluation of services managing vulval conditions.

5.2.4

Commissioners should work with the local health economy to develop local quality measurement frameworks for providers of dermatology services and should be involved in the development of PREMs and PROMs, which will provide a consistent approach to measuring and improving the quality of all services.

5.2.5

Service provision must include all aspects of the service, including prescribing and access to treatments. The stakeholder commissioning group should agree any changes in prescribing formularies and develop clear guidelines for the easiest access to all NICE-recommended treatments.

5.3 Key performance indicators

5.3.1

Evidence from providers of services managing vulval conditions that they have developed and implemented a patient and public involvement plan, including use of PREMs and PROMs, an effective patient panel, evidence of patient feedback and the provider's response to this.

5.3.2

Evidence of public and patient involvement when changes to services are proposed.

5.4 References

1. Department of Health (2010): Equity and excellence: liberating the NHS, Department of Health White Paper, London: The Stationery Office. Gateway ref. 14385. (Available at <http://tinyurl.com/2a8ljeo>)
2. Department of Health (2012): The NHS constitution for England (2012 version), London: The Stationery Office. Gateway ref. 17278. (Available at <http://tinyurl.com/ckjg5mx>)
3. Department of Health (2008) Guidance on the routine collection of patient reported outcome measures (PROMs) for the NHS in England 2009/10, London: Department of Health. (Available at <http://tinyurl.com/cy5qsc>)
4. See www.dermatology.org.uk/quality/dlqi/quality-dlqi.html.
5. Primary Care Commissioning (formerly NHS Primary Care Contracting) (2008): Providing care for patients with skin Conditions: Guidance and resources for commissioners: <http://tinyurl.com/b5x3apt>

THE APPENDICES



APPENDIX A

Membership of the project working group

Project working group

| Name | Role | Organisation/Region |
|---------------------|---|----------------------------|
| David Nunns | Project lead consultant gynaecological oncologist | BSSVD |
| Julia Schofield | Consultant dermatologist | Lincoln |
| Janet McLelland | Consultant dermatologist | Newcastle |
| Wendy Reid | Vice president education | RCOG |
| Deb Mandal | Chairman | BSSVD |
| Eman Toeima | Speciality doctor | Norwich |
| Andrew Watson | Consultant gynaecologist | Tameside |
| Elizabeth Venner | Associate specialist dermatology and genitourinary medicine | Truro |
| Antony Hollingworth | Consultant gynaecologist | London |
| Maggie Bartlett | GP | Keele |
| Kate London | Consultant dermatologist | Bradford |
| Sue Cooper | Consultant dermatologist | Oxford |
| Fenella Wojnarowska | President | BSSVD |
| Ruth Murphy | Consultant dermatologist | Nottingham |
| Suha Deen | Consultant pathologist | Nottingham |
| Fabia Brackenbury | Patient representative | Worldwide Lichen Sclerosus |
| Jyoti Dhar | Consultant genitourinary medicine | Leicester |
| Karen Gibbon | Consultant dermatologist | London |
| Jane Sterling | Consultant dermatologist | Cambridge |
| Elizabeth Derrick | Consultant dermatologist | Brighton |
| Cathy Green | Consultant dermatologist | Dundee |
| Elizabeth Carlin | Consultant genitourinary medicine | BASHH |
| Victoria Swale | Consultant dermatologist | London |
| Alan Tang | Consultant genitourinary Medicine | BASHH |
| Imali Fernando | Consultant genitourinary medicine | BASHH |
| Deepa Bansal | Consultant genitourinary medicine | BASHH |

Appendix B:

Guidance on appropriate practitioners and levels of care for vulval conditions

| Practitioner | Roles and responsibilities | Suggested conditions |
|---|--|--|
| General practitioner (GP) Level 2 care | Patient assessment (history taking, clinical examination, microbiological swabs) | Uncomplicated vulvovaginal infections (eg candidiasis) Follow-up of vulval conditions (eg uncomplicated lichen sclerosus) |
| Specialist care (dermatology, gynaecology, genitourinary medicine) Level 3 care | Patient assessment (history taking, clinical examination, microbiological swabs, biopsy) Treatment for common and uncommon conditions (eg lichen sclerosus, psoriasis) Follow-up Referral of certain patients to supra-specialist care (vulval service) | Skin disease (eg lichen sclerosus) Vulvodynia Unifocal VIN Complicated infections (ie resistant to basic treatment) |
| Supra-specialist care (vulval clinic) Level 4 care | Assessment and management of uncommon and rare skin disease | Uncommon conditions Vulval dermatoses (eg lichen planus – erosive, hypertrophic) Multifocal VIN Any patient with symptoms that do not respond to basic measures eg vulvodynia Rare conditions (eg bullous disorders) |
| Gynaecological cancer team Level 4 care | Patient assessment and treatment of pre-malignant and malignant vulval disease Liaison with the extended cancer team | Vulval cancer VIN (all types including Pagets disease) |

Appendix C:

Resources for women and health professionals

UK national guidelines for health professionals

| Comments | | Source |
|---|--|--|
| Vulvodynia guidelines | Produced by the UK BSSVD guidelines group (April 2009). | BSSVD website www.bssvd.org http://tinyurl.com/axdwzse |
| Management of Lichen Sclerosus | Produced by the British Association of Dermatologists (updated 2010). | British Association of Dermatologists website www.bad.org.uk http://tinyurl.com/a4oprur |
| Framework for the management of vulval skin disorders | An evidence-based framework for improving the initial assessment and care of women with vulval disorders. Guidance for the general gynaecologist, with advice on when to refer to the specialist multidisciplinary team as the most efficient link to other services, such as a patch test clinic, psychosexual counsellors or reconstructive surgeons (2011). | Royal College of Obstetricians and Gynaecologists website www.rcog.org.uk http://tinyurl.com/bx6zpf8 |
| Management of vulvovaginal candidiasis | From the Clinical Effectiveness Group, British Association for Sexual Health and HIV (2007). | BASHH website www.bashh.org http://tinyurl.com/bkzwpfq |
| Management of vulval disease | From the British Association for Sexual Health and HIV, guidance on the management of lichen sclerosus, lichen planus, VIN, vulval pain and Paget's disease (2007). | BASHH website www.bashh.org www.bashh.org/documents/113/113.pdf |
| Management of vulval cancer | Evidence-based guidelines from the RCOG on the management of vulval cancer (2006). | Royal College of Obstetricians and Gynaecologists website www.rcog.org.uk http://tinyurl.com/azxp2cg |

Websites for health professionals

| | Comments | Source |
|--|--|---|
| International Society for the Study of Vulval Disease | Contains many patient information leaflets, and information on international meetings. Registration required. | http://tinyurl.com/anlt2zc |
| British Association of Dermatologists | Contains lichen sclerosus guidelines and has patient information leaflets on lichen sclerosus, lichen planus, vulval skin care, vulvodynia and vestibulodynia | Available at www.bad.org.uk |
| 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. | Available at www.ecsvd.eu |
| Royal College of Obstetricians and Gynaecologists | Professional organisation for gynaecologists. | Available at www.rcog.org.uk |
| British Association of Sexual Health | Professional organisation for GUM physicians. | Available at www.bashh.org |
| British Association of Gynaecological Pathologists | Professional association for pathologists, with newsletters, meetings, networking. | Available at www.thebagp.org |
| College of Sexual and Relationship Therapists (formerly BASRT) | Good links for patients on psychosexual dysfunction, including information on finding a therapist. | Available at www.cosrt.org.uk |
| Association of Chartered Physiotherapists in Women's Health | A UK-based clinical interest group specialising in women's health. Useful for finding a physiotherapist for women with vulval pain who need pelvic floor muscle assessments/biofeedback. | Available at www.csp.org.uk/ |

Patient groups and factsheets

| | Comments | Source |
|------------------------------------|---|---|
| Worldwide Lichen Sclerosus Support | Support and information for women and men with lichen sclerosus Also has site for Paget's disease | www.lichensclerosus.org (downloadable factsheet available here) www.vulvapagetssupport.org |
| UK Lichen Planus | Support and information for women and men with lichen planus, including non-genital LP | www.uklp.org.uk (downloadable factsheet available here) |
| Vulval Pain Society | Support and information for women with vulvodynia. Contains information on workshops for women and links to patient support groups | www.vulvalpainsociety.org |
| Vulval Health Awareness Campaign | A charity devoted to vulval health, includes information on self-examination. | www.vhac.org (downloadable leaflet available here) |
| National Vulvodynia Association | US nonprofit organisation to improve the lives of individuals affected by vulvodynia. Education, networking, support, awareness and advocacy. | www.nva.org |

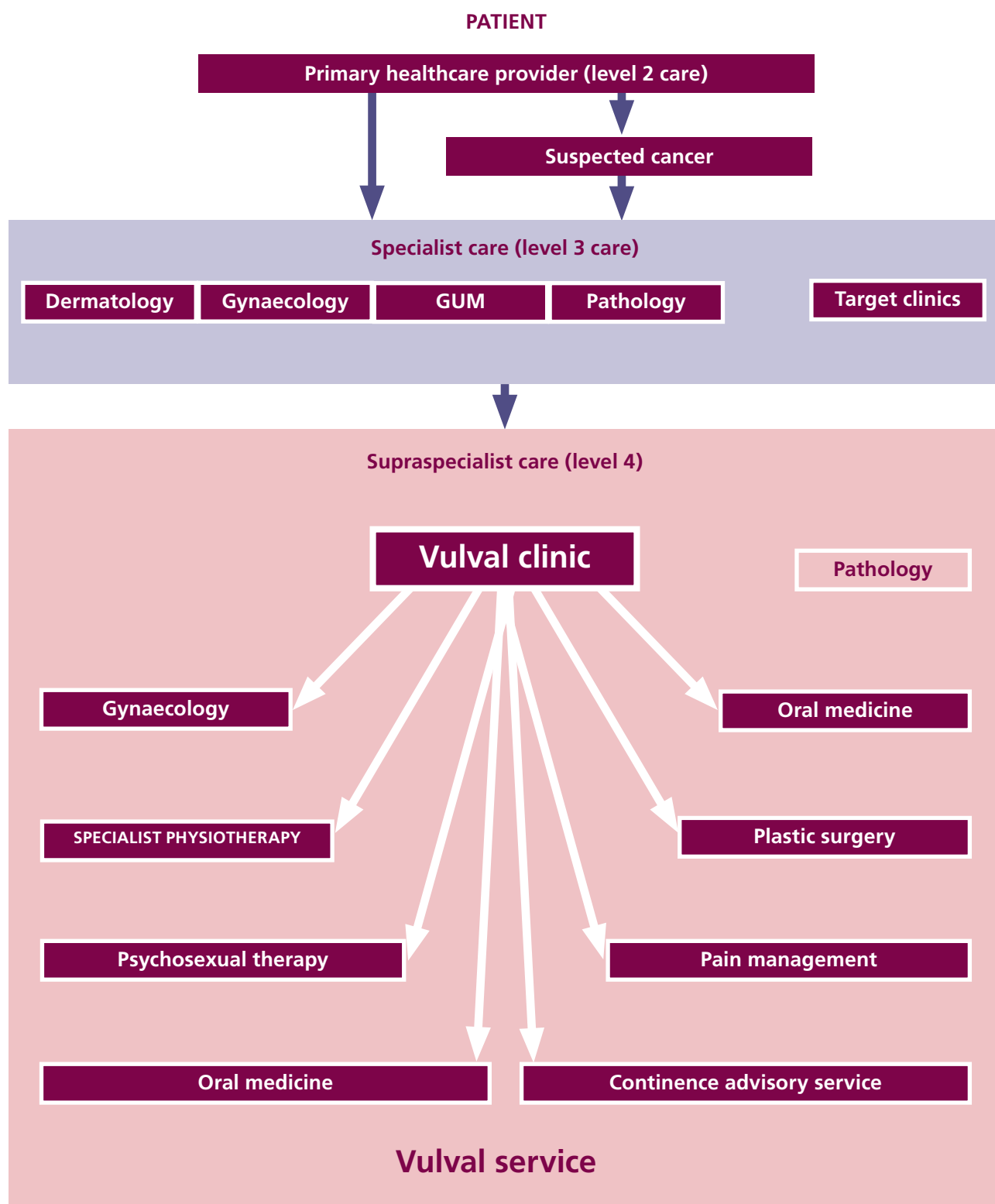
Training courses

| | Comments | Source |
|--|---|---|
| Genital disorders modules in the dermatology e-learning project | Online training course which is free for UK doctors to access. | http://tinyurl.com/a5kg7eb |
| University of Hertfordshire vulval disease course (March annually) | Two-day short course for healthcare professionals keen to know more about vulval problems. Content delivered over two days by a multi-disciplinary group of well-known experienced healthcare professionals working in dermatology, gynaecology and sexual health and includes significant patient input. The teaching programme has been designed to meet the requirements for basic training in vulval disorders for specialist registrars working in dermatology, gynaecology and sexual health. | http://tinyurl.com/aexmj7b Or contact: Madeleine Flanagan, email: m.flanagan@herts.ac.uk Telephone: 01707 286400 Vanessa Mason, email: v.r.mason@herts.ac.uk Telephone: 01707 284665 |
| StratOG | From the RCOG, on online module for gynaecologists working towards passing the MRCOG. Payment required. | http://tinyurl.com/a9nwpoo |
| International Society for the Study of Vulval Disease | ISSVD vulval postgraduate course which is usually attached to the world congress. | http://tinyurl.com/bzw2l4r |

Textbooks on vulval disease

| Publication details | Comments |
|---|---|
| <i>The vulva</i> , eds Sallie Neill & Fiona Lewis, Wiley Blackwell. ISBN 978-1-4051-6813-7 | Comprehensive. Clear text and many pictures of vulval disease |
| <i>Obstetric and gynaecologic dermatology</i> , ed. Martin Black, Mosby Elsevier. ISBN 978-0-7234-3445-0 | Comprehensive. Clear text and many pictures of vulval disease (contains useful CD of images). |
| <i>The vulva and vagina manual</i> ed. Graeme Dennerstein, Taylor & Francis ISBN, 978-0-6464-4531-1 | Comprehensive. Clear text and many pictures of vulval disease |

Appendix D: Models of care for women with vulval conditions



Appendix E: Suggested audits

1. Adherence to national evidence-based guidelines (eg from NICE and audits from specialist societies).

2. Review of database collection of patients diagnosed from a vulval service.

3. Has a biopsy been performed in patients with clinically active lichen sclerosus that has not responded to treatment?

4. Are follow-up arrangements in place for patients with ongoing symptomatic disease?

5. Are patients with genital lichen sclerosus aware of the need to report any suspicious lesions within the affected skin?

Glossary of abbreviations

| | |
|-------|---|
| BAD | British Association of Dermatologists |
| BASHH | British Association for Sexual Health and HIV |
| BSSVD | British Society for the Study of Vulval Disease |
| COSRT | College of Sexual and Relationship Therapists |
| CPD | Continuing professional development |
| CME | Continuing medical education |
| DH | Department of Health |
| GMC | General Medical Council |
| GP | General practitioner |
| GUM | Genitourinary medicine |
| KSF | Knowledge skills framework |
| MDT | Multidisciplinary team |
| NICE | National Institute for Health and Clinical Excellence |
| PREM | Patient-recorded experience measure |
| PROM | Patient-recorded outcome measure |
| RCOG | Royal College of Obstetricians and Gynaecologists |
| VIN | Vulval intraepithelial neoplasia |

