

E10/S(HSS)/b

**2013/14 NHS STANDARD CONTRACT
FOR RECONSTRUCTIVE SURGERY SERVICE FOR ADOLESCENTS WITH
CONGENITAL MALFORMATION OF THE FEMALE GENITAL TRACT**

PARTICULARS, SCHEDULE 2 – THE SERVICES, A – SERVICE SPECIFICATION

Service Specification No.	E10/S(HSS)/b
Service	Reconstructive surgery service for adolescents with congenital malformation of the female genital tract
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Congenital abnormalities of the genital tract are uncommon. It is recognised that patients with these conditions not only present with physical symptoms but they also suffer psychological difficulties so they need a holistic and multidisciplinary approach to their care ⁽¹⁾.

Nadarajah et al ⁽²⁾ confirmed the effectiveness of dilator therapy for the treatment of vaginal agenesis and the American College of Obstetricians and Gynaecologists Committee opinion is that medical dilator therapy is the first choice treatment ⁽³⁾ therefore surgery may no longer be necessary. The success rate of this non-surgical treatment at the Centre is approximately 95%, under one-to-one supervision and guidance of a clinical nurse specialist ⁽⁴⁾. It is also increasingly recognised that patients with Mayer Rokitansky Kuster Hauser (MRKH) syndrome have huge psychological issues and they benefit from both a one-to-one counselling, as well as group therapy ⁽⁵⁾. The younger patients with obstructive conditions do not normally suffer any psychological sequelae when they and their parents are appropriately informed and supported and when their physical symptoms are corrected at the onset without unnecessary delay or inappropriate treatment ⁽⁷⁾.

2. Scope

2.1 Aims and objectives of service

Congenital abnormalities of the genital tract in young females are uncommon to rare. The rate of incidence for the different categories can vary from 1:5,000 to 1:15,000 and some are even more complex and rare, so it is important that these young patients are only referred to a highly skilled and experienced team of experts to ensure their correct diagnoses and treatment and prevent unnecessary detrimental and adverse effect on their anatomical function and reproductive health;

Adolescence and young adulthood is a difficult transitional phase for some girls, therefore discovering that they have an abnormal condition that impacts on their sexuality and fertility often causes significant psychological difficulties in addition to their physical symptoms. They commonly suffer from confusion, isolation, anger and depression and often feel like “freaks” so it is unsurprising that some girls become introverted or have behavioural changes or experience denial because they have difficulty coping with their newly diagnosed conditions. This adds to the complexity of their treatment and management so it is vital to treat both physical and psychological symptoms if they are to have a chance of leading normal lives. Many of the patients also require continued support throughout or at different stages of their lives so it is vital that the service provides ongoing patient support to ensure their psychological stability and wellbeing. This requires a dedicated multidisciplinary team and an ongoing varied patient support system such as helpline, websites, chat-room and online support, patient contacts and support group, updated literature and newsletters;

The aim of the service is to provide efficient, seamless and holistic diagnosis and management to maximise the function and wellbeing of the patients by:

- establishing and maintaining anatomical function;
- enabling normal sexual function;
- enhancing and preserving reproductive health;
- increasing fertility opportunities and successful fertility outcomes;
- enhancing psychological health and preventing long-term sequelae;
- maximising treatment outcomes;
- enhancing patient experience.

Objectives and Expected Outcomes:

To provide the highest quality of care and an efficient and seamless service to patients with congenital abnormalities of the genital tract, their families and their partners. This requires a holistic service encompassing teamwork and a highly specialised multidisciplinary team approach in order that these patients and their parents/families receive the best and appropriate information, advice, treatment and support throughout, thus optimising their treatment outcomes, patient experience and overall wellbeing;

Additionally the service acts as an expert resource and link for all healthcare professionals nationally.

2.2 Service description/care pathway

Description of the disease/condition:

Congenital abnormalities of the genital tract may be divided into these categories:

- congenital absence of the vagina & associated structures (**Mayer- Rokitansky-Kuster-Hauser syndrome (MRKH)**)
- congenital obstructive outflow tract abnormalities (absent cervix, vaginal septum, imperforate hymens and rudimentary uterine horns)
- congenital abnormalities of the vulva/virilisation of the external genitalia (congenital adrenal hyperplasia)
- XY females (androgen insensitivity, gonadal dysgenesis, hermaphrodites).

Service description:

The service provides comprehensive, expert diagnosis and management for patients with congenital abnormalities of the genital tract, including continued support for the patients, their parents and partners. Additional support is provided through a helpline and website;

The specialist multidisciplinary team must include:

- consultant gynaecologists with an expertise in this field (male and female, for patients' preference)
- clinical nurse specialist
- clinical psychologist

This core team must be supported by designated experienced staff including:

- paediatricians;
- radiologists;
- anaesthetists;

Patients must be seen and assessed by the core team and supporting clinicians in order that both physical and psychological issues are identified and addressed, as part of their holistic management;

Where prior screening/imaging (MRI) is required, this may be performed at their local hospitals or can be arranged for them at the host trust;

Patients who have been seen previously (when they were younger) can re-engage with the service by contacting the centre directly, without having to go through their GPs or original referring doctors again to avoid any possible barriers to on-going appropriate management. When the service resumes responsibility for managing the patient, the service must inform the patient's GP through communication of the particular issues and the proposed management plan;

The treatment programme for all patients must be planned to accommodate patients' school or work commitments unless surgical treatment is deemed urgent. This is key

to the service provision because it minimises the interruptions to their schooling and treatment is planned when they are psychologically ready, which increases treatment adherence and successful treatment outcomes;

Single rooms (with en suite facilities) must be provided for all the patients to preserve their privacy and confidentiality. All adolescent patients are visited by the paediatric staff and play leaders to ensure that all their needs are met whilst they are in hospital. One or both parents of the <16year old adolescent girls are advised to stay with their daughters. Accommodation is provided separate to this specification by the trust;

Patients must be reviewed pre and post operatively by the core team and given written information of their conditions and diagrams of the findings of their operations, to ensure their full understanding. In addition, they must receive ongoing support and advice throughout their hospital stay and after discharge by the clinical nurse specialist;

Patients who are admitted for medical dilator treatment must have one-to-one supervision with the clinical nurse specialist - their admission, discharge and follow-up reviews are arranged directly with them. They are also supported by the clinical psychologist and have direct access to them, since the treatment of both physical and psychological aspects are essential and complimentary elements of the patient's management;

The patients are reviewed regularly by the multidisciplinary team until they complete their treatment because this continued support increases motivation and maximises treatment adherence ⁽⁶⁾. Patients must be encouraged to be directly involved with their treatments and taught to assess their progress. Additional support and advice must be available post discharge from hospital and patients have direct access to the provider via a helpline and online support (website). They also have the option of one-to-one patient support;

Apart from the one-to-one counselling and professional support from a psychologist with appropriate expertise, another vital part of their management is patient group therapy ⁽⁵⁾. The centre has a patient support group with a membership of over 550 girls/women and they have meetings twice a year. The meetings are organised for patients and their families/partners and always facilitated by the team (consultant, clinical nurse specialist and psychologist), which they preferred because they found the professional presence, advice and support reassuring and helpful (evaluation/feedback from each meeting). Patients and families also have the opportunity to meet others with the same condition and to share their experiences with each other, and consistently stated that they found this extremely helpful because they did not feel so "alone" ⁽⁷⁾ and their families/partners also shared this benefit.

Risk management:

Care delivered by the service must be of a nature and quality to meet the care standards, specification and Agreement for the service. It is the trust's responsibility

to notify the commissioner on an exceptional basis should there be any breaches of the care standards. Where there are breaches any consequences will be deemed as being the trust's responsibility;

Patients must be managed in line with the specification and care standards. Any deviation from these which has not been approved by NHS England is at the trust's risk both clinically and financially. It is the trust's responsibility to inform the commissioners of any such non-approved deviations on an exceptional basis;

Where a patient's presentation challenges the assumptions that underpin the specification, service standards and contractual arrangements it is the trust's responsibility to inform the commissioners on an exceptional basis, prior to any treatment (except for emergency treatment) so that the implications of the patient's requirements can be considered. This does not affect situations where the Individual Funding Application process applies.

Service model and care pathways: see Appendix 1

Days/hours of operation

- Working hours: Monday – Friday, 09.00hrs – 17.00hrs
- Helpline: voicemail facility for messages for outside working hours
- Website: online support daily except weekend and public holidays
- Designated Clinics: Specialist team clinic (Tuesdays, 13.00hrs – 17.00hrs)
- Nurse-led clinics by clinical nurse specialist (Wednesdays, 09.30hrs – 13.00hrs) (Alternate Fridays 0930-1130)
- Clinical psychologist (Tuesdays and Wednesdays, all day)
- Theatres (Wednesdays, 13.00hrs – 17.00hrs)

Discharge criteria & planning including any transition arrangements

Discharge planning for elective interventions should be initiated and shared with the patient and/or their parents, so that they can plan school and/or work commitments.

Medical patients

Patients must be seen by a competent clinician prior to discharge.

Patients must be reviewed as an outpatient two weeks post discharge and then at 4-6 week intervals until it is clinically appropriate move away from this regime

All patients must be given appropriate advice and information on the management of their condition plus details of how to access further medical and emotional support

Discharge summaries must be sent to GPs on the day of discharge from hospital.

Surgical patients

- Patients must be seen by a specialist consultant from the core multi-disciplinary team (MDT) prior to discharge;

- Patients must be given appropriate post-operative advice (e.g. mobilising, pain management, nutrition and resumption of normal activities) by a competent professional from the core MDT;
- Patients must be reviewed as an outpatient 6 weeks post discharge;
- All patients must be given appropriate advice and information on the management of their condition plus details of how to access further medical and emotional support;
- Discharge summaries must be sent to GPs on the day of discharge from hospital.

2.3 Population covered

This service is for all females with congenital abnormalities of the genital tract in England, Scotland and eligible European Union (EU) citizens. Patients from Wales and Northern Ireland are treated under separate contract arrangements.

2.4 Any acceptance and exclusion criteria

Accessibility/acceptability:

- The service is accessible to any female with congenital abnormalities of the genital tract irrespective of age, culture, disability and gender;
- Providers require staff to have attended child protection training i.e. Safeguarding Children Level 3;
- Professional translators and signers must be used for patients who require these facilities.

Referral criteria, sources and routes:

- All patients have an initial professional referral from GPs, local or national consultants, (gynaecologists or different disciplines) for diagnoses, treatment, counselling and psychological support and other patient supports;
- Direct transfers from other NHS hospitals and trusts – consultant to consultant telephone referral or via clinical nurse specialist at the centre re: adolescents requiring emergency surgeries for congenital obstructive conditions;
- Other healthcare professionals (psychologists and clinical nurse specialists from other disciplines) can also refer patients;
- Patients known to the service or previously treated may self-refer (for further information on their conditions or fertility issues, counselling, patient-to-patient support or support group).

Exclusion criteria:

There are no exclusion criteria as all patients with congenital abnormalities of the genital tract are seen and treated appropriately when they are referred to the service.

Response time & detail and prioritisation

All clinically urgent cases are admitted to the gynaecology ward and reviewed by the core team consultants within 24 hours. All routine outpatient appointments are made within six weeks of referral.

2.5 Interdependencies with other services

- The service is accessible to any female with congenital abnormalities of the genital tract residing in England and Scotland. Patients are commonly referred by their local consultants, GPs or other healthcare professionals. The referrals may be sent in by post or faxed directly to the appropriate clinic or directly to the consultants. The clinic is also accessible via Choose & Book;
- Patients residing in Wales and N. Ireland are funded by their respective Health Boards;
- Patients who are known to us (previously seen or treated) can self-refer;
- Other doctors, healthcare professionals and patients nationally access the helpline and websites for information, advice and to join the website/chat-room and the patient support group.

Relevant networks and screening programmes

None

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

The nationally designated service must be fully integrated into their trust's corporate and clinical governance arrangements.

The commissioners and service will conduct a formal Joint Service Review at least every six months.

Continual service improvement plan

The service is required to demonstrate continual improvement in patient care and service delivery. This process will be informed by clinical and service audit, patient and public engagement and awareness of national and international clinical and policy developments that could inform service development.

The service will agree service development improvement plans with NHS England and demonstrate progress at Joint Service Review meetings.

4. Key Service Outcomes

Quality & Performance Standards

The provider will provide agreed performance monitoring data on a monthly basis. Where any elements of this data deviate from the agreed plan, the service will provide a brief explanation accompanying the submission of the report. The commissioner may wish to follow this up and request further information to inform any necessary actions that will be agreed between the service and commissioners in the context of the terms and conditions of the Agreement.

5. Location of Provider Premises

Location(s) of Service Delivery

- Queen Charlotte's and Chelsea Hospital
- Imperial College Healthcare NHS Trust

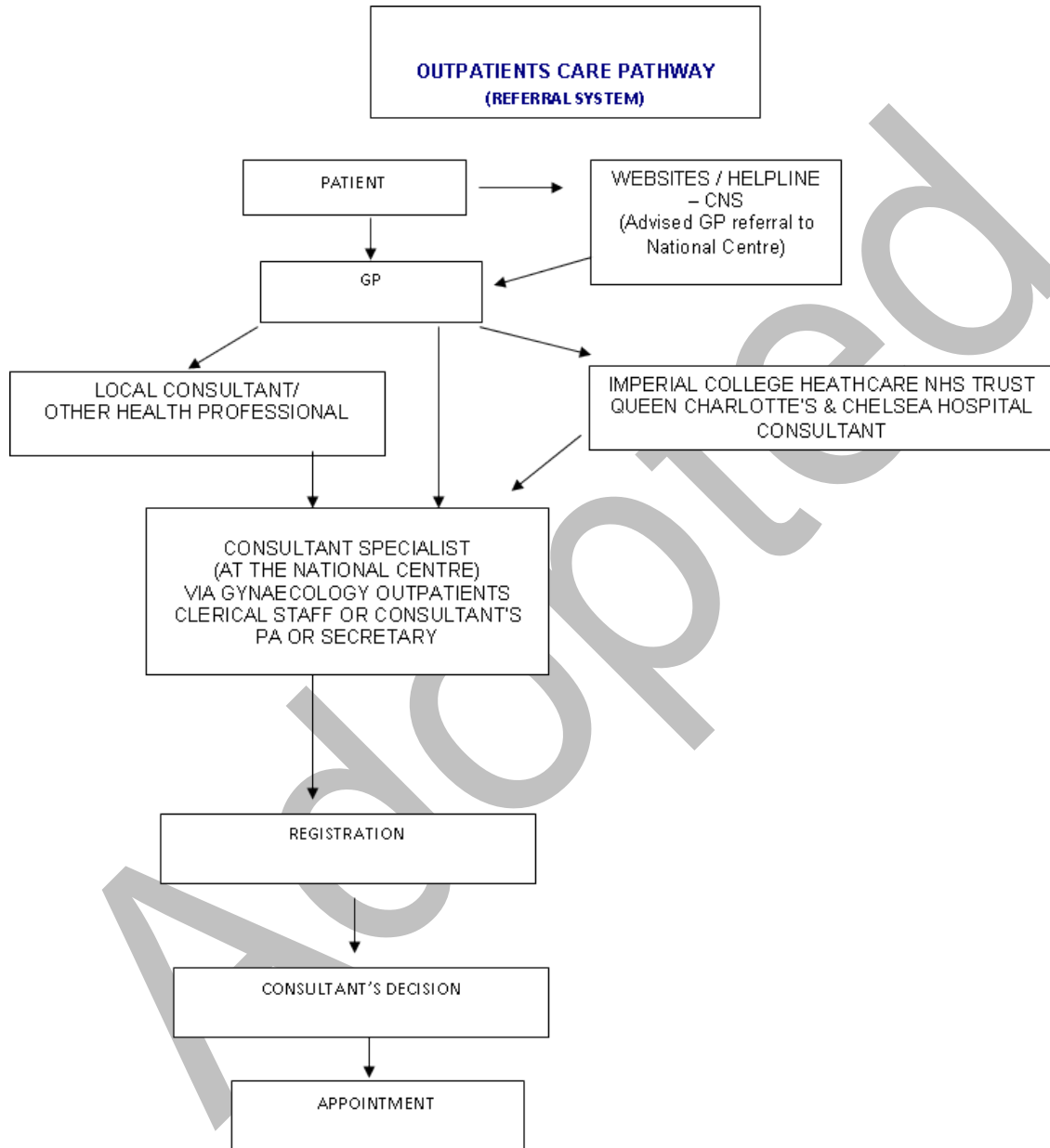
Sub-contractors

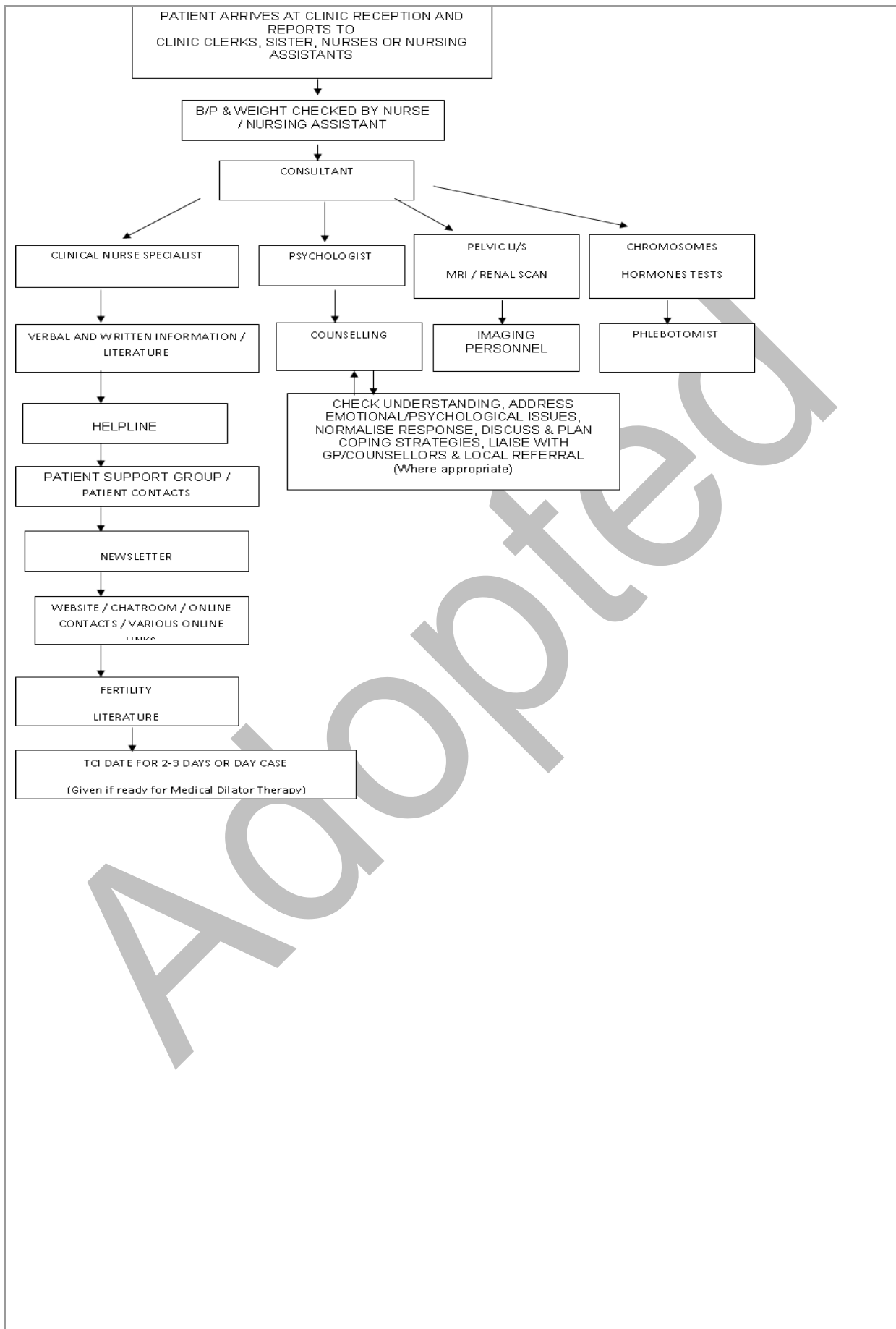
- None

Adopted

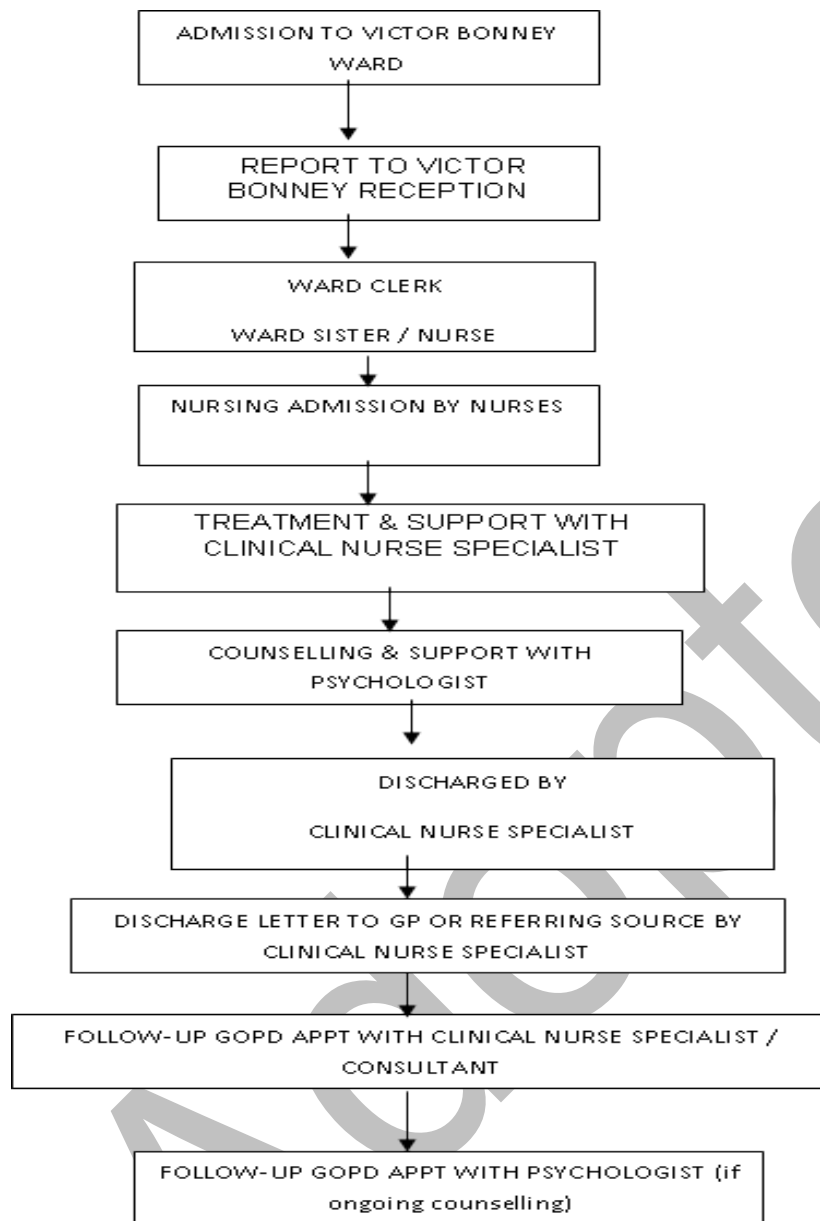
Appendix 1

PATIENT CARE PATHWAY FOR MEDICAL TREATMENT (DILATOR THERAPY/PSYCHOLOGICAL INPUT)

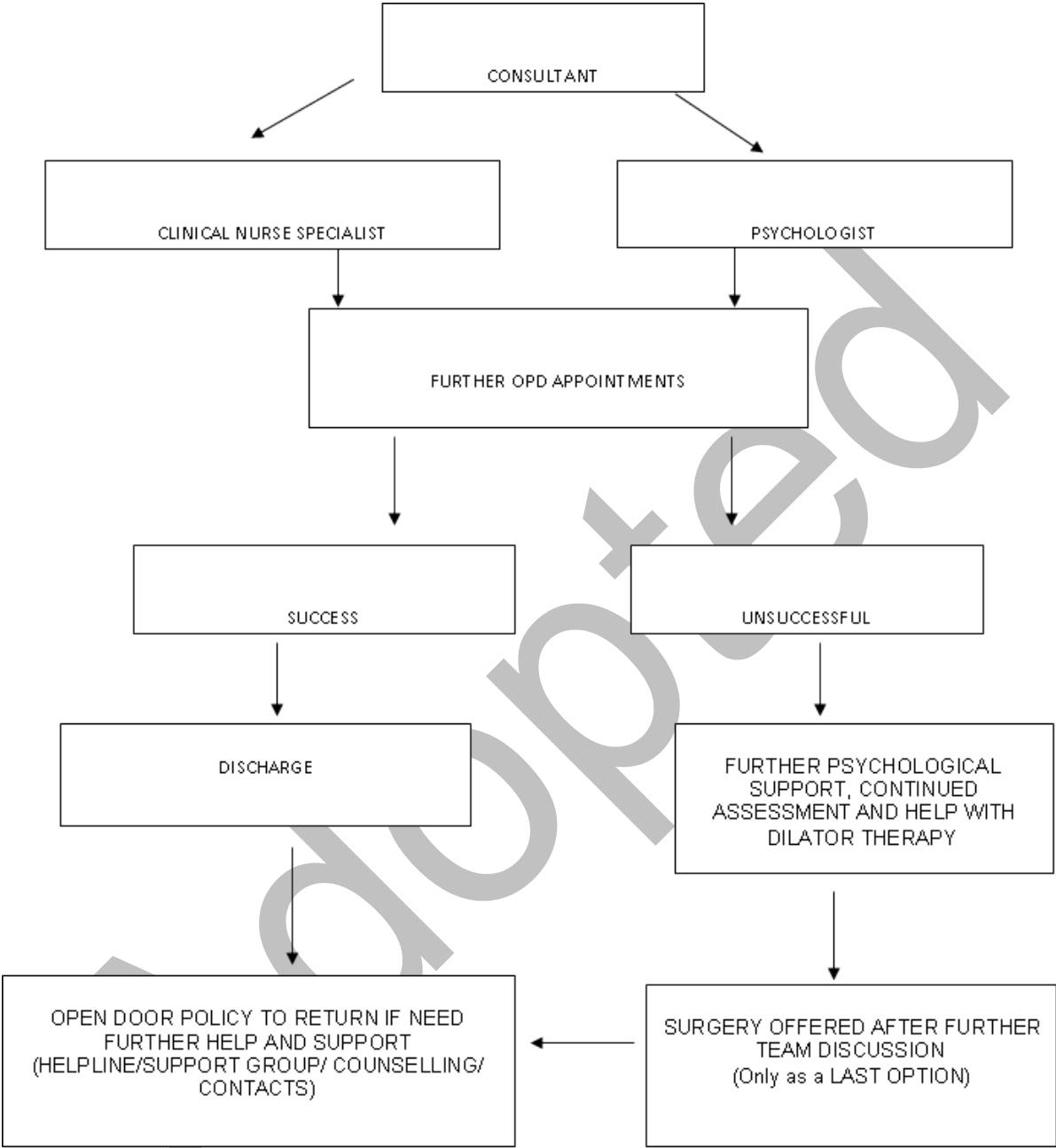




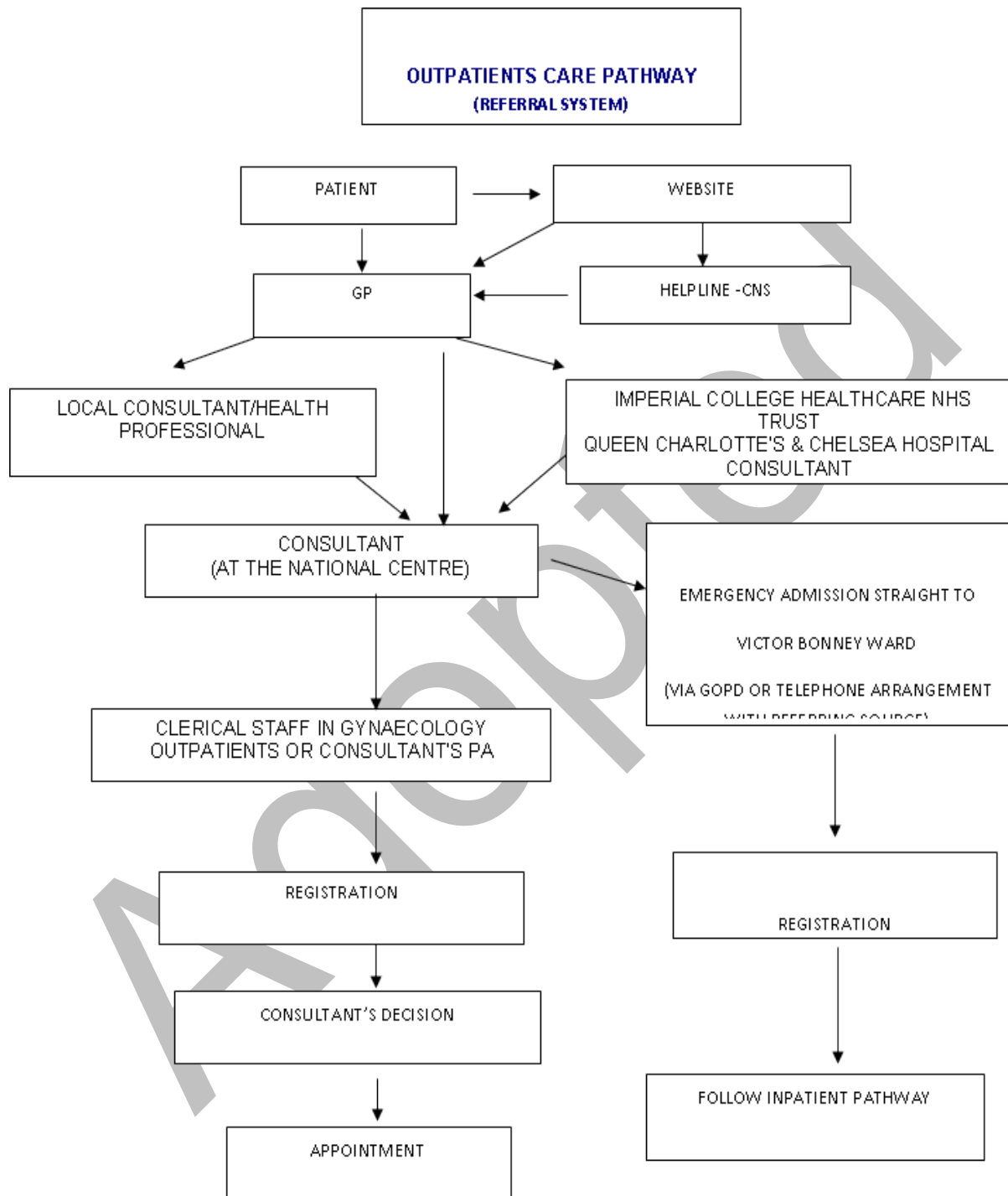
INPATIENT CARE PATHWAY FOR MEDICAL TREATMENT (DILATOR THERAPY/PSYCHOLOGICAL INPUT)

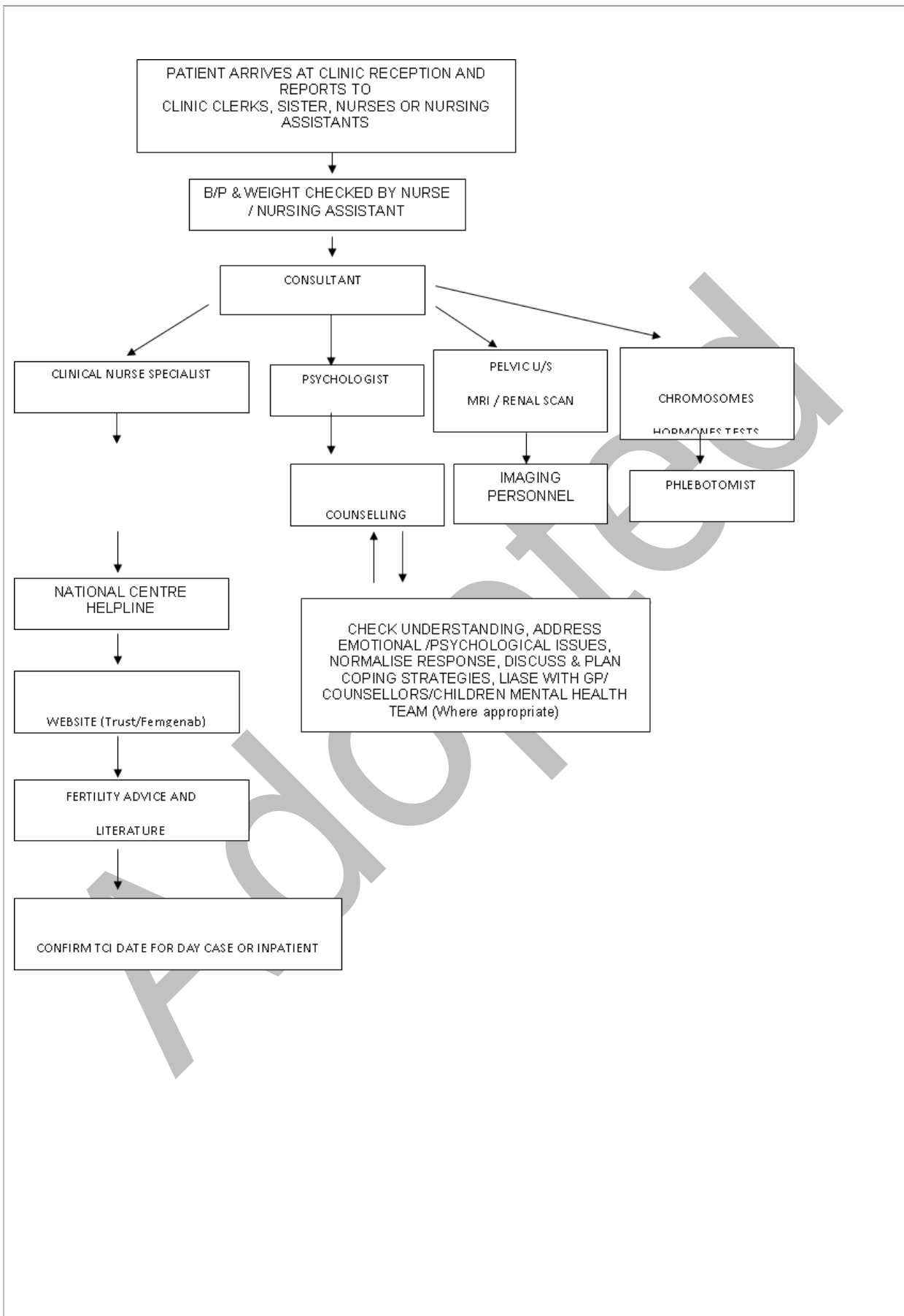


Outpatients review and evaluation of medical treatment

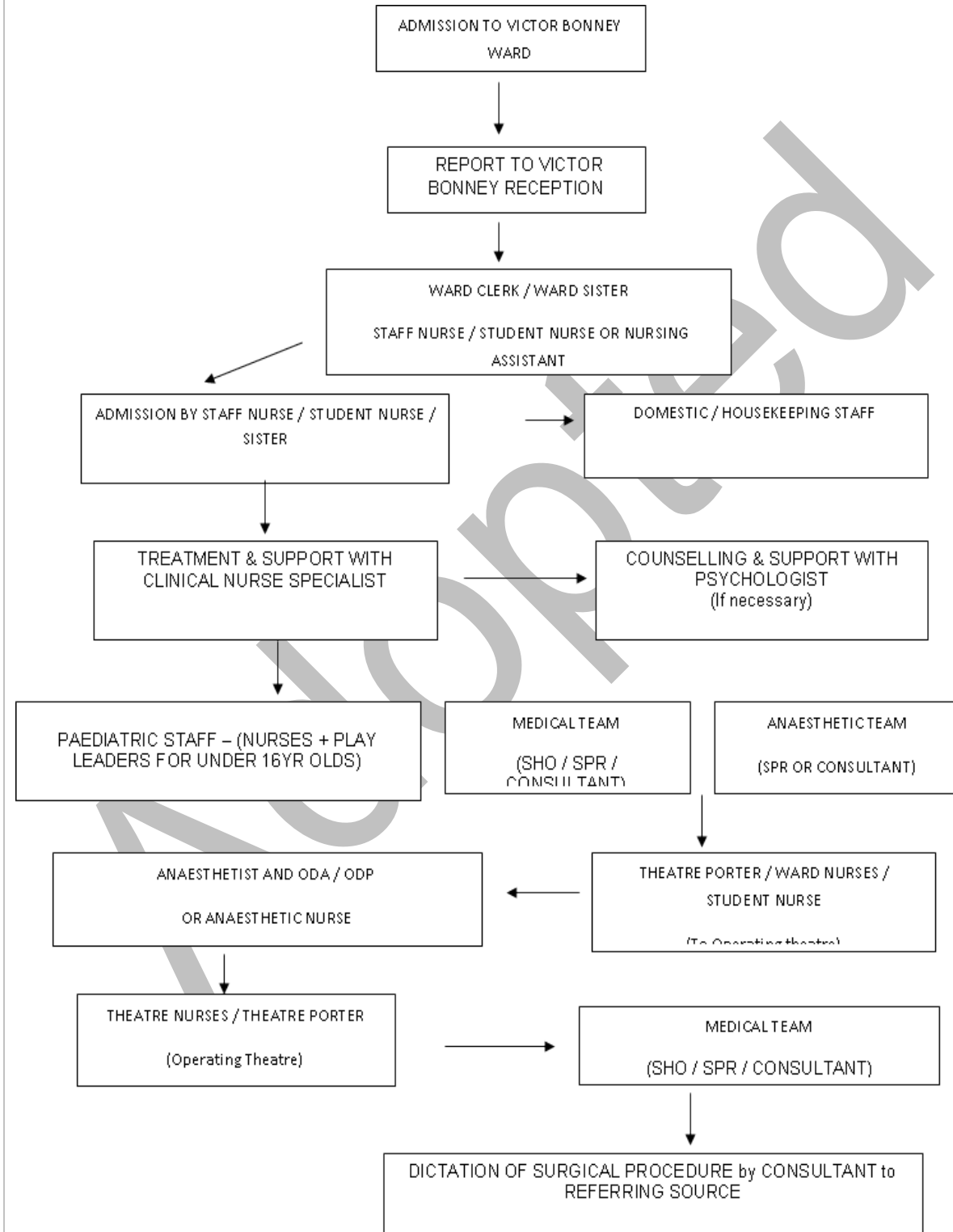


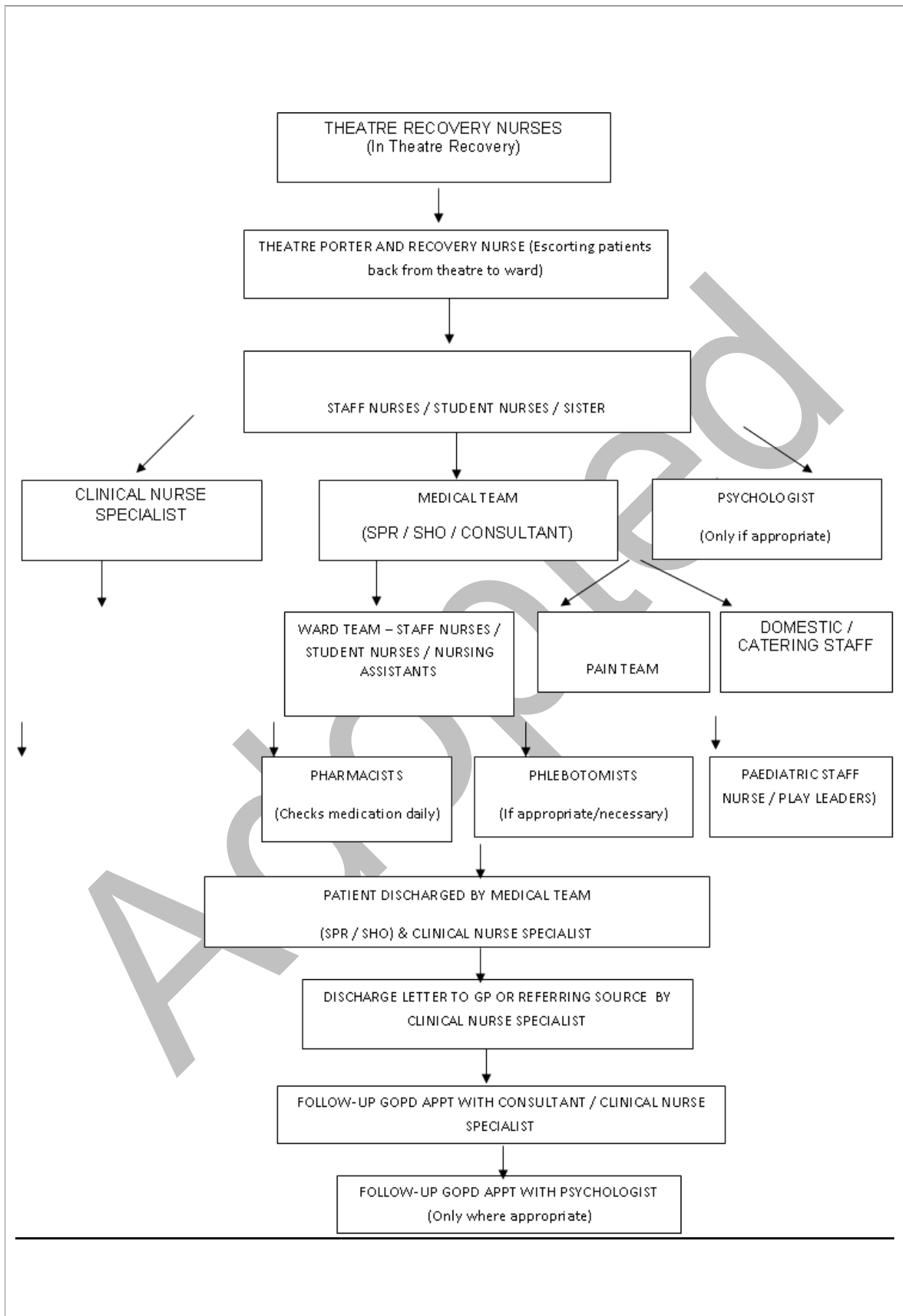
Patient care pathway for surgical treatment



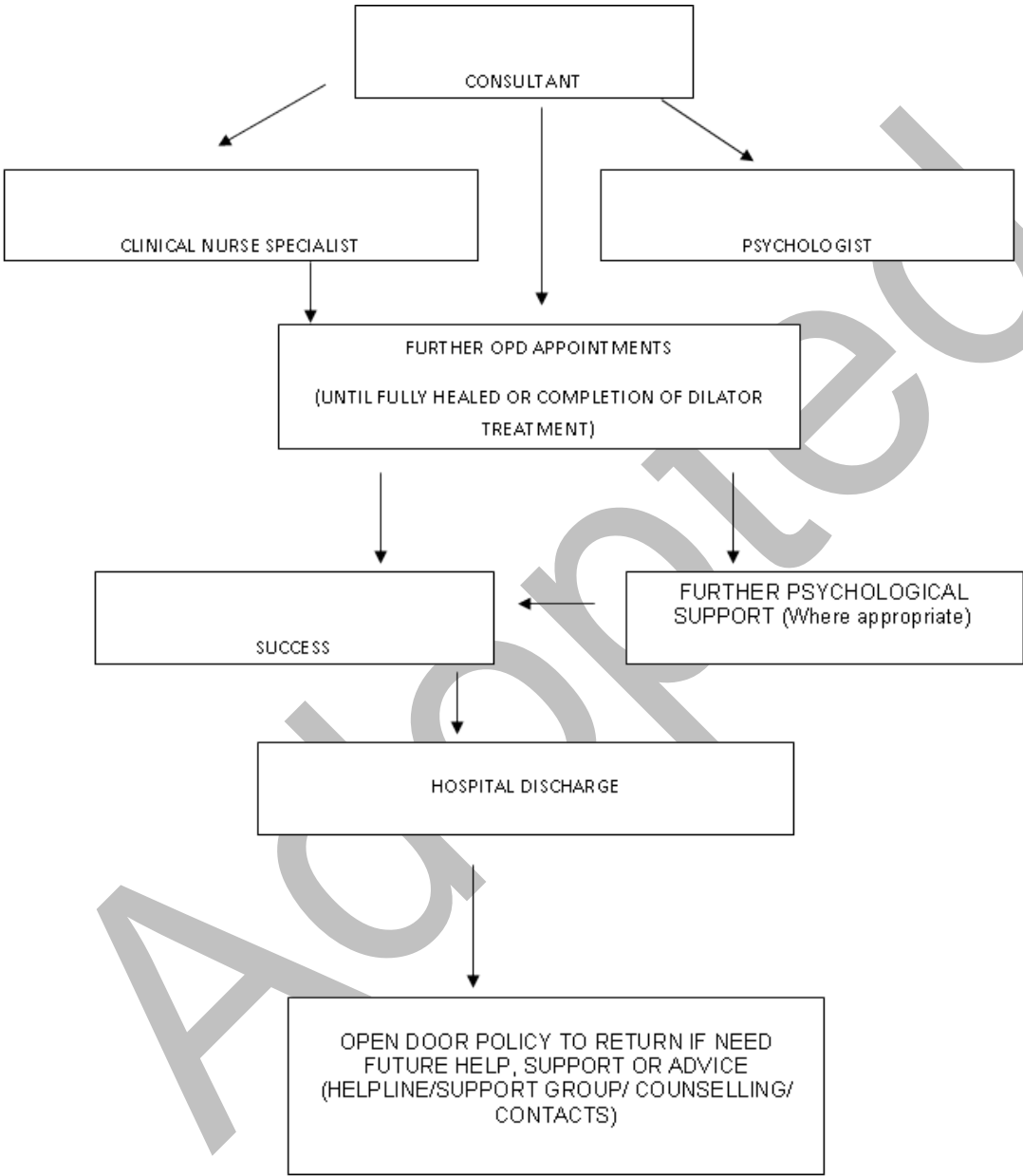


Care pathway for surgical treatment (inpatient pathway)





Outpatients review and evaluation of surgical treatment



**THE NATIONAL CENTRE FOR ADOLESCENT AND ADULT FEMALES WITH
CONGENITAL ABNORMALITIES OF THE GENITAL TRACT**

CARE PATHWAY FOR MEDICAL TREATMENT
(DILATOR THERAPY/PSYCHOLOGICAL INPUT)

1 REFERRAL SYSTEM

(Please tick appropriate box)

- GENERAL PRACTITIONER
- LOCAL CONSULTANT / OTHER HEALTH PROFESSIONAL
- TRUST CONSULTANT / TRUST HEALTH PROFESSIONAL

2 OUTPATIENT PATHWAY

(Please tick box where appropriate)

- REFERRAL LETTER SENT DIRECTLY BY POST TO GYNAE OPD CLERICAL STAFF / CONSULTANT'S PA
- REFERRAL LETTER FAXED DIRECTLY TO GYNAE OUTPATIENTS CLERICAL STAFF / CONSULTANT'S PA
- PATIENT IS REGISTERED BY OPD CLERICAL STAFF (on ICHIS and notes)
- CONSULTANTS SEE & PRIORITISE LETTERS – URGENT OR ROUTINE APPT
- URGENT APPT MADE & SENT (within 2 weeks)
- ROUTINE APPT MADE & SENT (within 6 weeks)

3 CLINIC CONSULTATION

(Please tick box where appropriate)

- PATIENT REPORTS AT CLINIC RECEPTION TO CLERICAL / NURSING STAFF WITH HER APPT LETTER (clinic clerks, OPD sister, nurses or nursing assistants)
- PATIENT'S DETAILS CHECKED AND CONFIRMED ON ICHIS & NOTES

(Name, marital status, address, telephone/contact numbers/GP details)

- PATIENT'S B/P, WEIGHT & HEIGHT RECORDED BY NURSE OR NURSING ASSISTANT

- PATIENT SEEN BY CONSULTANT
- PATIENT SEEN BY CLINICAL NURSE SPECIALIST
- TCI DATE GIVEN WHERE APPROPRIATE
- PATIENT SEEN BY COUNSELLING PSYCHOLOGIST
- IMAGING BY RADIOLOGIST OR ULTRASOUND SONOGRAPHER – PELVIC ULTRASOUND SCAN / MRI SCAN / RENAL SCAN (if requested by consultant)
- BLOOD TESTS BY PHLEBOTOMISTS (if necessary and requested by consultant)

SUPPORT FACILITIES FOR PATIENTS REQUIRING MEDICAL TREATMENT

(Information to be given after consultation with Consultant, Clinical Nurse Specialist, Psychologist or GOPD nursing staff – please tick box where appropriate)

- VERBAL INFORMATION & PATIENT INFORMATION LEAFLETS
- HELP-LINE
- PATIENT SUPPORT GROUP
- NEWSLETTER (sent together with invitations for support group meetings)
- PATIENT CONTACTS
- MRKH WEBSITE / ONLINE CHATROOM
- FERTILITY INFORMATION (eg. IVF Surrogacy and Adoption)
- COUNSELLING BY PSYCHOLOGIST
- TCI DATE (for patients who are ready for treatment)
- NO IMMEDIATE TREATMENT (give instructions for when they are ready to start treatment)
- ACCOMODATION ARRANGEMENTS FOR PARTNERS / PARENTS

INPATIENT PATHWAY

(Please tick box appropriate)

MEDICAL TREATMENT (DILATOR THERAPY/PSYCHOLOGICAL INPUT):

- REPORT TO VICTOR BONNEY WARD (ward clerk, ward sister or nursing staff)
- ADMISSION BY NURSING STAFF (staff nurse/nursing assistant on ICHIS & documentation)
- TREATMENT WITH CLINICAL NURSE SPECIALIST & TRAINED NURSING STAFF:
- DAY CASE
- 2 – 3 DAYS STAY
- COUNSELLING & ADDRESSING EMOTIONAL/PSYCHOLOGICAL ISSUES
- HOSPITAL DISCHARGE (date of discharge on nursing documentation and ICHIS)
- DISCHARGE LETTER TO GP AND REFERRING SOURCE (by SHO or SPR)
- FOLLOW-UP GOPD CLINIC APPOINTMENT (with clinical nurse specialist and consultant)
- FOLLOW-UP GOPD COUNSELLING APPOINTMENT (with psychologist)

OUTPATIENTS PROGRESS REVIEW

- TREATMENT AND PROGRESS REVIEW (by clinical nurse specialist and consultant)
- FURTHER GOPD APPOINTMENTS (until completion of treatment)

EVALUATION OF MEDICAL TREATMENT

- SUCCESS
- DISCHARGE FROM HOSPITAL
- OPTION TO RETURN IF FURTHER HELP, ADVICE AND SUPPORT REQUIRED IN THE FUTURE (HELPLINE, SUPPORT GROUP, PATIENT CONTACTS, MRKH WEBSITE & CHATROOM AND COUNSELLING ALWAYS AVAILABLE AT ANY STAGE OF THEIR LIVES)

- UNSUCCESSFUL
- FURTHER PSYCHOLOGICAL SUPPORT
- FURTHER CONTINUED ASSESSMENT AND HELP WITH DILATOR THERAPY
- SURGERY (only if all help and support have been exhausted)

Clinical Nurse Specialist
National Centre for Congenital Abnormalities of the Genital Tract
Queen Charlotte's & Chelsea Hospital
The Imperial College Healthcare NHS Trust
Du Cane Road
London W12 0HS

Helpline/Direct-line: 020 3313 5363

Web-sites: www.mrkh.org.uk