USPAL Network Core Principles & Requirements

Purpose

This document outlines the core principles of the US Pregnancy After Loss (USPAL) Network, which is a member of the International Rainbow Clinic Network (IRCN). All members of the USPAL Network annually certify their alignment with these principles. Further details are found in the USPAL Network Protocol.

Principles

1. **Patient profile**: The Network's core is providing care to patients with a history of pregnancy loss.
2. **Equity**: The Network strives to ensure that equitable, high-quality care in pregnancy after loss is available to all.
3. **Care team**: Network care teams are multidisciplinary and able to provide high-quality medical care and emotional support to patients.
4. **Training**: Network clinic staff undergo specialized training in caring for people who are pregnant after loss and maintain key competencies with annual refresher training.
5. **High-quality, individualized care**: Network clinics operate according to special protocols, allowing for customization by clinic and patient.
6. **Mental healthcare and peer support**: Network clinics ensure integration of mental healthcare and peer support with medical healthcare.
7. **Research**: The Network tracks patient outcomes and supports high-quality, collaborative research, with Network clinics participating as their resources permit.
8. **Quality assurance**: Network clinics complete a rigorous onboarding process and are annually recertified.

Requirements

1. **Patient profile**: The Network's core is providing care to patients with a history of pregnancy loss.
    (a) Network clinics accept patients with a history of
        i. stillbirth,
        ii. neonatal death, and
        iii. termination of pregnancy.
    (b) Additional patient types may also be accepted (e.g., women with a history of multiple miscarriages, loss at 16-20 weeks, severe placental insufficiency, preterm birth, traumatic birth experience, etc.); this is determined by each clinic.
    (c) Patients (parents and babies) and patient charts (paper and electronic) are clearly identified as USPAL Network Clinic patients.
2. **Equity**: The Network strives to ensure that equitable, high-quality care in pregnancy after loss is available to all.
    (a) All Network clinic patients are provided with the same type and quality of care regardless of their insurance status.
    (b) Mandatory specialized training includes sensitivity to different patient profiles.
    (c) Telehealth may be provided to increase access for patients in remote areas or with limited availability.
3. **Care team**: Network care teams are multidisciplinary and able to provide high-quality medical care and emotional support to patients.
    (a) Network clinic teams are multidisciplinary. The Core Team includes:

i. The Lead Clinician, who is an MFM, Obstetrician, or Certified Nurse Midwife (with a named back-up MFM or OB, who would be available for consultation as needed);
ii. Additional clinicians who provide patient care, including L&D staff who deliver PAL babies and NICU staff who provide care to PAL NICU babies;
iii. Sonographer(s) who provide sonography services to PAL patients;
iv. Other allied health professionals who interact with PAL patients (e.g. RNs, NPs, PAs, MAs);
v. Clinic managers;
vi. Support staff (e.g. front desk staff, schedulers, IT specialists, billing, etc.) who interact with PAL patients; and
vii. Trainer Team (parent trainer and clinician educator).

(b) It is strongly encouraged that teams also include:
i. mental healthcare providers (e.g. psychiatrist, psychologist, social worker) and
ii. peer support specialists (e.g. layperson peers, community health worker peers).

(c) Clinics which opt into the joint research program (see 7b) also have a lead PI and staff to gather, manage, and transfer data, and to approach patients for research studies.

(d) Additional specialties (e.g. nutritionists, endocrinologists, ED) may also be on the team.

(e) All clinic staff can interact with patients in a way that ensures high-quality emotional support due to mandatory training (see 4 below).

4. **Training**: Network clinic staff undergo specialized training in caring for people who are pregnant after loss and maintain key competencies with annual refresher training.

(a) The Core Team (see 3a above) receives training prior to the clinic's joining the Network.
i. This training is delivered by the Network.
ii. During it, the clinic's Trainer Team (which includes both a parent trainer and a clinician educator) are trained in how to deliver the specialized training.
iii. They then carry out their own training of additional clinic staff under the supervision of the Network's lead trainer and are certified by the lead trainer.

(b) After the clinic has joined the Network, its Trainer Team delivers all further specialized training in-house. This is called 'ongoing training'. Ongoing training includes
i. onboarding training for new staff on the Core Team and
ii. an annual refresher training for already-trained staff on the Core Team.
iii. It may also include training for non-core staff.

(c) Training covers:
i. the definitions and disease burdens (physical and mental) of stillbirth, newborn death and related pregnancy outcomes at state, national and global levels;
ii. why and how the USPAL model was developed and the basics of the protocol;
iii. the perspective and needs of PAL patients and how to interact in ways that improve patient experience and support patients' mental health.

5. **High-quality, individualized care:** Network clinics operate according to special protocols, allowing for customization by clinic and patient, including:

(a) Longer and more frequent appointments as needed and as logistically possible;
(b) More frequent ultrasounds and antepartum surveillance as needed;
(c) Continuity of care when possible (strongly preferred);
(d) Integration of medical healthcare with mental healthcare and peer support;
(e) Care provision by specially trained providers and support staff;

(f) Regular patient counseling that covers
    i. prenatal surveillance
    ii. timing and mode of birth
    iii. fetal movement monitoring
    iv. emotional support
    v. planning for the current or a future pregnancy, including genetic screening/testing, anatomy scans, serial fetal growth scans, etc., depending on the patient's lifelong health, keeping in mind that the entire family system of partners, siblings, and extended family members is also affected by stillbirth and infant loss.

(g) A full review of what is known about the prior loss(es) (including placental pathology, autopsy, genetic and other test results);

(h) Acknowledgement of the importance of integrating parent voice into the care team.

6. **Mental healthcare and peer support**: Network clinics ensure integration of mental healthcare and peer support with medical healthcare. All clinics:
   (a) Carry out EPDS screening for depression and anxiety at (1) intake, (2) postpartum visits and (3) continued potential screening (PHQ9 is acceptable if the EPDS is not possible);
   (b) Ensure the intake visit covers key points related to mental health;
   (c) Provide patients with an up-to-date resource list including access to peer support and mental healthcare for all patient profiles, including online support;
   (d) Have a referral mechanism to appropriate mental healthcare;
   (e) Provide patients with a list of resources for 24-hour access to emergency mental health and peer support (e.g. hotline numbers);
   (f) Ensure that the above care is documented in patient records in such a way as to enable other members of the care team to understand patients' mental health status and follow up as needed.
7. **Research**: The Network tracks patient outcomes and supports high-quality, collaborative research, with Network clinics participating as their resources permit.
   (a) All clinics facilitate data collection using Network-provided tools on
      i. patient experience and
      ii. training quality.
   (b) Clinics with interest and capacity are encouraged to also join the Network's collaborative research program. This requires
      i. signing a data-sharing agreement with the Secretariat (University of Utah) and
      ii. collecting a Minimum Dataset.
   (c) All clinics, including those who opt out of the collaborative research program, also report regularly to the Secretariat on basic data (a small number of data items) on:
      i. clinic operations;
      ii. birth outcomes; and
      iii. mental health outcomes.
8. **Quality assurance**: Network clinics complete a rigorous onboarding process and are annually recertified. All clinics:
   (a) Have been unanimously approved by the USPAL Network Secretariat;
   (b) Self-certify their adherence to key requirements annually; and
   (c) May be removed if in violation of these requirements.