Making the experience of prenatal diagnosis better together:

A research and training framework for improving psychosocial outcomes of expectant parents.

Shakes, P. (James Cook University & Through the Unexpected) & Johnson, B. (RMIT University)
contact: pieta.shakes@jcu.edu.au

Project conception

While prenatal screening and diagnostic technologies have advanced, psychosocial aspects have not received similar attention (Hodgson & McClaren, 2018). Receiving news that their baby may need medical care, have a disability or have a life-limiting condition can throw parents into emotional crisis (Aite et al., 2011). This initial shock can be followed by acute or enduring mental health challenges.

The risk of overlooking the psychosocial aspects of prenatal diagnosis in training and guidelines also harbours consequences for health and allied health professionals. High rates of burnout and moral distress were connected to the challenging work within prenatal diagnosis, confounded by a lack of training and support (Menezes et al., 2013; Thomas et al., 2017).

There is an evident need for health and allied health professional training for working with parents who receive or have received unexpected news about the health, development or genetics of their unborn baby.

Research program establishment

Evidence highlights the need for multidisciplinary training specifically related to the psychosocial aspect of prenatal diagnosis, however, there remain gaps in knowledge about contemporary experiences and perspectives. This knowledge is required to ensure that training addresses the needs of health and allied health professionals working with parents who receive or have received a possible or confirmed prenatal diagnosis of a fetal anomaly or variation.

Furthermore, there are gaps in knowledge required to ensure the training also addresses the priorities, needs and wishes of parents who have lived experience of receiving a prenatal diagnosis.

A research program led by **Dr Belinda Johnson (RMIT)** was commenced to reduce these gaps in knowledge. The results will be used to inform the development of the module topics, learning outcomes and module content for the training program.

Study 1: Perspectives of health and allied health professionals

Study 2: Perspectives of people with lived experience of receiving unexpected news

Advisory group recruitment

Health & allied health professionals, researchers and people with lived experience were recruited to provide oversight and a range of perspectives and insights at various stages of the training development.

Learning sequence design

A design thinking process was adopted for the initial development of the learning sequence.

Empathise: Learners will be health and allied health professionals around Australia who work with parents at any stage of pregnancy, following a termination for medical reasons and/or early parenting.

Module development

Informed by the prior literature and the embedded research program, the modules will be collaboratively produced by teams of experts through research, practice and lived experience. The development of the learning outcomes, activities, and the content will be supported by academics with experience in online postgraduate health professional education design and delivery.

Please scan the QR code to view the up-to-date record of collaborating organisations and individuals, and the project advisory group. You can also express your interest to participate, as this project will be *Better Together.*
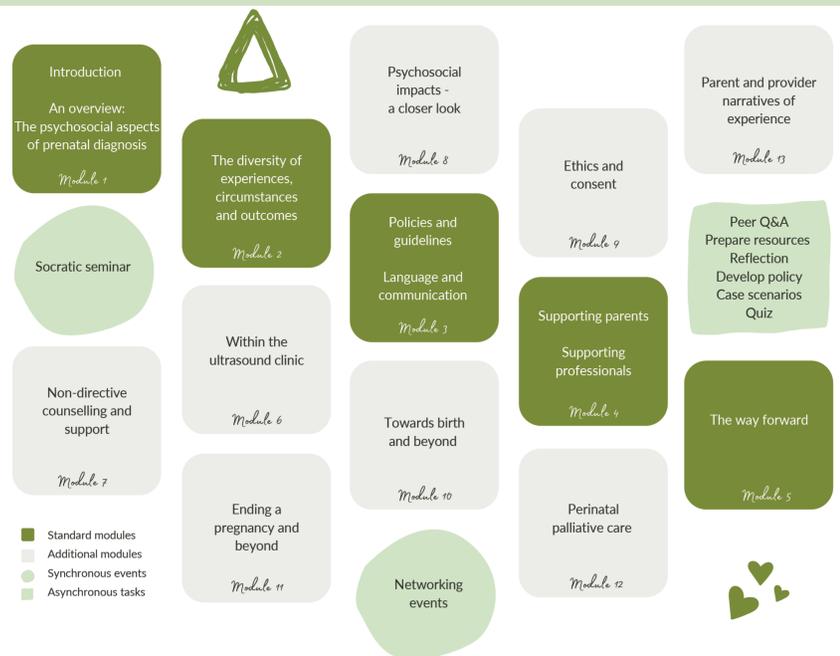
Commenced /completed

To be commenced

Figure 1. Initial proposed modules for multidisciplinary online training about the psychosocial aspects of prenatal diagnosis

Introduction
An overview: The psychosocial aspects of prenatal diagnosis
Module 1

Socratic seminar

Non-directive counselling and support
Module 7

The diversity of experiences, circumstances and outcomes
Module 2

Policies and guidelines
Language and communication
Module 3

Within the ultrasound clinic
Module 6

Ending a pregnancy and beyond
Module 11

Psychosocial impacts - a closer look
Module 8

Ethics and consent
Module 9

Supporting parents
Supporting professionals
Module 4

Towards birth and beyond
Module 10

Networking events

Perinatal palliative care
Module 12

Parent and provider narratives of experience
Module 13

Peer Q&A
Prepare resources
Reflection
Develop policy
Case scenarios
Quiz

The way forward
Module 5

Standard modules
Additional modules
Synchronous events
Asynchronous tasks

Define: Short online learning courses often default to a knowledge-transmission or content-focused style. Within this training, we will build upon constructivist, humanistic and transformative learning theories to harness the expertise and experience of the learners.

Ideate: Progress through this stage of design thinking led to the decision for online module-based learning with multimedia content complemented by authentic and engaging learning activities that engender hope, critical thinking and the translation of learning into practice.

Training launch

An initial introductory module will be launched ahead of the full program and will be available for free participation through the **Centre of Perinatal Excellence (COPE)** training platform.

The full training program is anticipated to launch in July 2023. This launch time depends on the project funding, research progress and respects the flexibility required to commit to the co-design process.

Production

The team will continue the design thinking process through the production of the multi-sensorial learning materials for the co-designed modules. The high-fidelity prototype will be tested by potential learners and reviewed by parents with lived experience of receiving a potential or confirmed prenatal diagnosis.

Evaluation

The evaluation of the training project will receive oversight from **Associate Professor Chris Maylea (La Trobe University)**. Both process and outcomes will be evaluated, with a focus on the innovative design of the short online learning sequence, and learner engagement and experience.

Aite, L., Zaccara, A., Mirante, N., Nahom, A., Trucchi, A., Capolupo, I., & Bagolan, P. (2011). Antenatal diagnosis of congenital anomaly: a really traumatic experience? *Journal of Perinatology, 31*(12), 760-763. https://doi.org/10.1038/jp.2011.22

Hodgson, J., & McClaren, B.J. (2018). Parental experiences after prenatal diagnosis of fetal abnormality. *Seminars in Fetal and Neonatal Medicine, 23*(2), 150-154. https://doi.org/10.1016/j.siny.2017.11.009

Menezes, M. A., Hodgson, J. M., Sahhar, M., & Metcalfe, S. A. (2013). "Taking its toll": the challenges of working in fetal medicine. *Birth, 40*(1), 52-60. https://doi.org/10.1111/birt.12029

Thomas, S., O'Loughlin, K., Clarke, J., & Schumacher, U. (2017). The 21st century sonographer: Role ambiguity in communicating an adverse outcome in obstetric ultrasound. *Cogent Medicine, 4*(1). https://doi.org/10.1080/2331205x.2017.1373903

Scan for more info & to register for updates

Through the Unexpected

JCU — JAMES COOK UNIVERSITY AUSTRALIA

RMIT UNIVERSITY