

HOW DO PATIENTS MAKE DECISIONS?

AN INNOVATIVE PATIENT WORKSHOP TO INFORM CODESIGN OF A DECISION SUPPORT WEBSITE ABOUT GENETIC CANCER RISK

Kelly Kohut^{1,2*}, Kate Morton¹, Karen Hurley³, Lesley Turner⁴, on behalf of the CanGene-CanVar Patient Reference Panel^{**}, on behalf of the International Lynch Decision Aid Stakeholder Panel^{***}, Diana Eccles⁵, Claire Foster¹



¹ Centre for Psychosocial Research in Cancer: CentRIC, School of Health Sciences, University of Southampton, Southampton, UK; ² St George's University Hospitals NHS Foundation Trust, London, UK; ³ Stanford R Weiss, MD Center for Hereditary Colorectal Neoplasia, Cleveland Clinic, Cleveland, USA; ⁴ Patient and public collaborators; ⁵ Faculty of Medicine, University of Southampton, Southampton, UK

Introduction

Patient decision aids (PtDA) complement shared decision-making with healthcare professionals and improve decision quality. However, PtDA often lack theoretical underpinning. We codesigned a PtDA to help people with increased genetic cancer risks manage choices. The aim of an innovative workshop described here was to engage with the people who will use the PtDA regarding the theoretical underpinning and logic model outlining our hypothesis of how the PtDA would lead to more informed decision-making.

Methods

Patients with lived experience were involved in codesign and coproduction of this workshop and analysis as partners and co-authors. Patient discussions were the primary data source. The premise of this workshop was to prioritise the importance of patient lived experience: to listen, learn, then reflect together to understand and propose ideas to improve patient care through codesign of a PtDA. Short presentations about psychological and behavioural theories by an expert were interspersed with facilitated, small group discussions led by patients. Patients were asked what is important to them when they make health decisions, what theoretical constructs are most meaningful and how this should be applied to codesign of a PtDA. An artist created a visual summary (Figure 1). Notes from patient discussions and the artwork were analysed using reflexive thematic analysis.

Results

The overarching theme was: It's personal (Figure 2). Contextual factors important for decision-making were varied and changed over time. There was no one 'best fit' theory to target support needs, suggesting an inductive, flexible framework approach to programme theory would be most effective. The PtDA logic model was revised based on patient feedback (Figure 3).

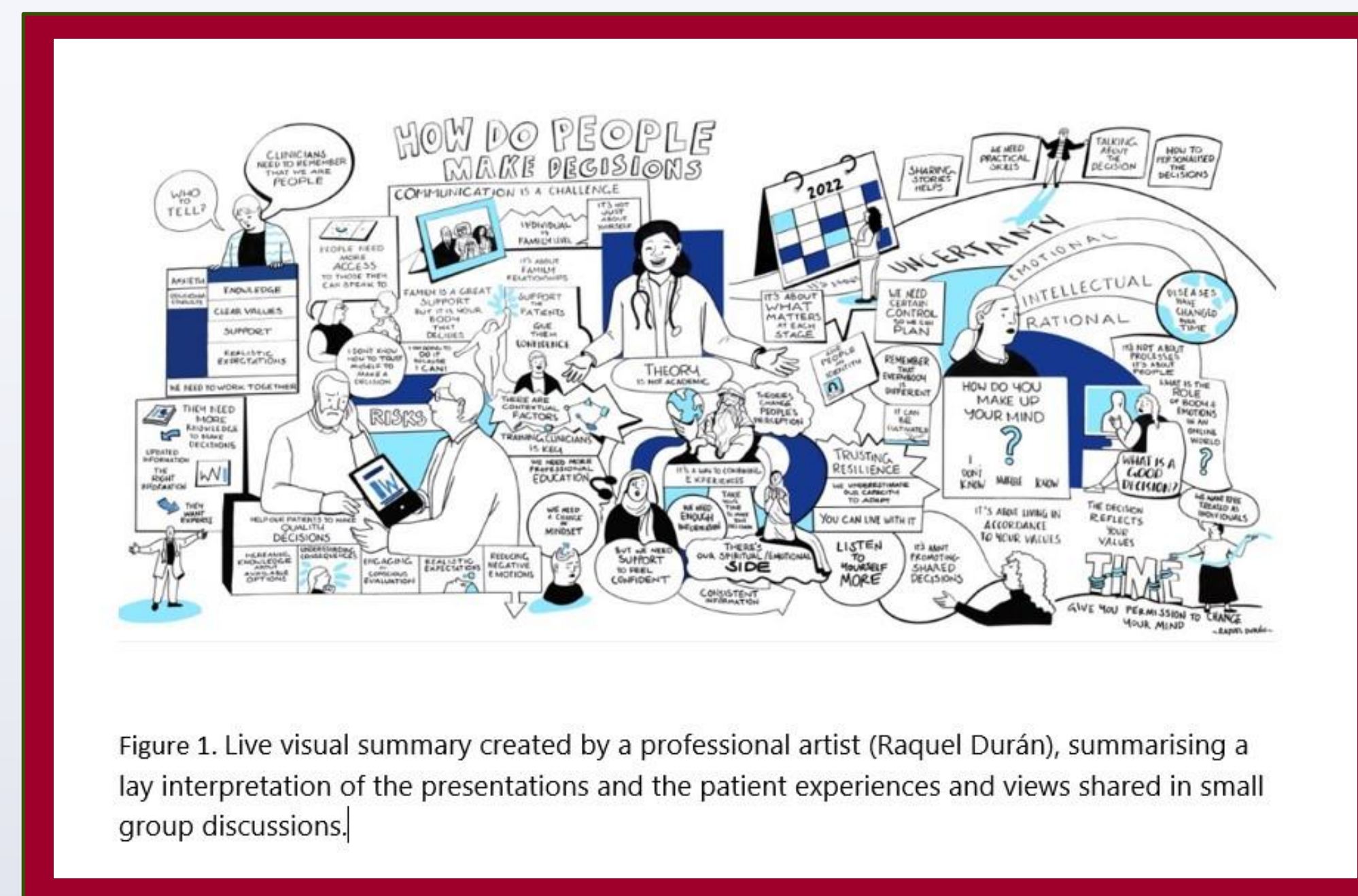


Figure 1. Live visual summary created by a professional artist (Raquel Durán), summarising a lay interpretation of the presentations and the patient experiences and views shared in small group discussions.

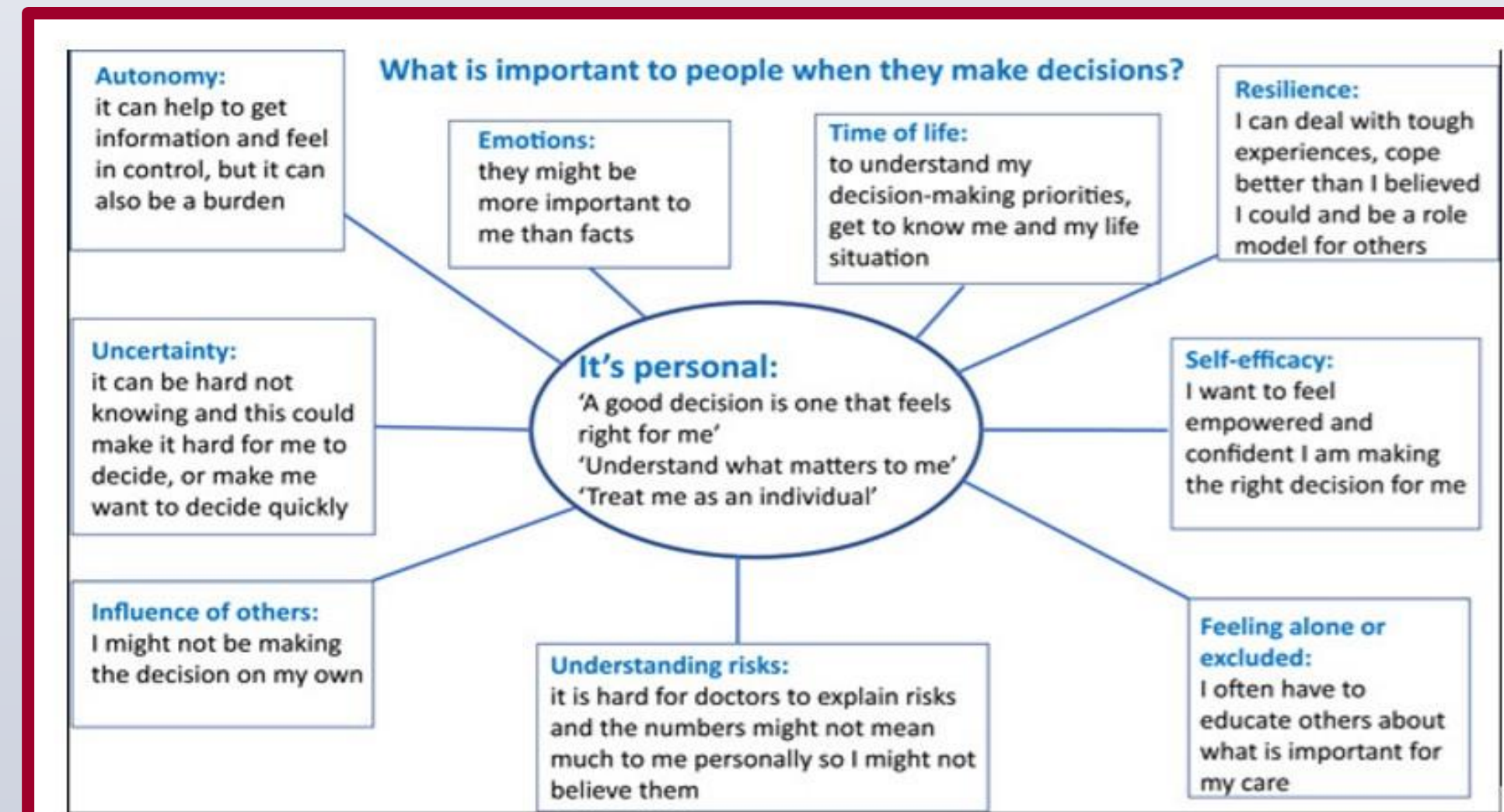


Figure 2. What is important to people when they make decisions? Schematic map of subthemes (shown in boxes): autonomy, emotions, time of life, resilience, self-efficacy, feeling alone/excluded, understanding risks, influence of others and uncertainty. In the centre (shown in an oval) is the overarching theme: It's personal.

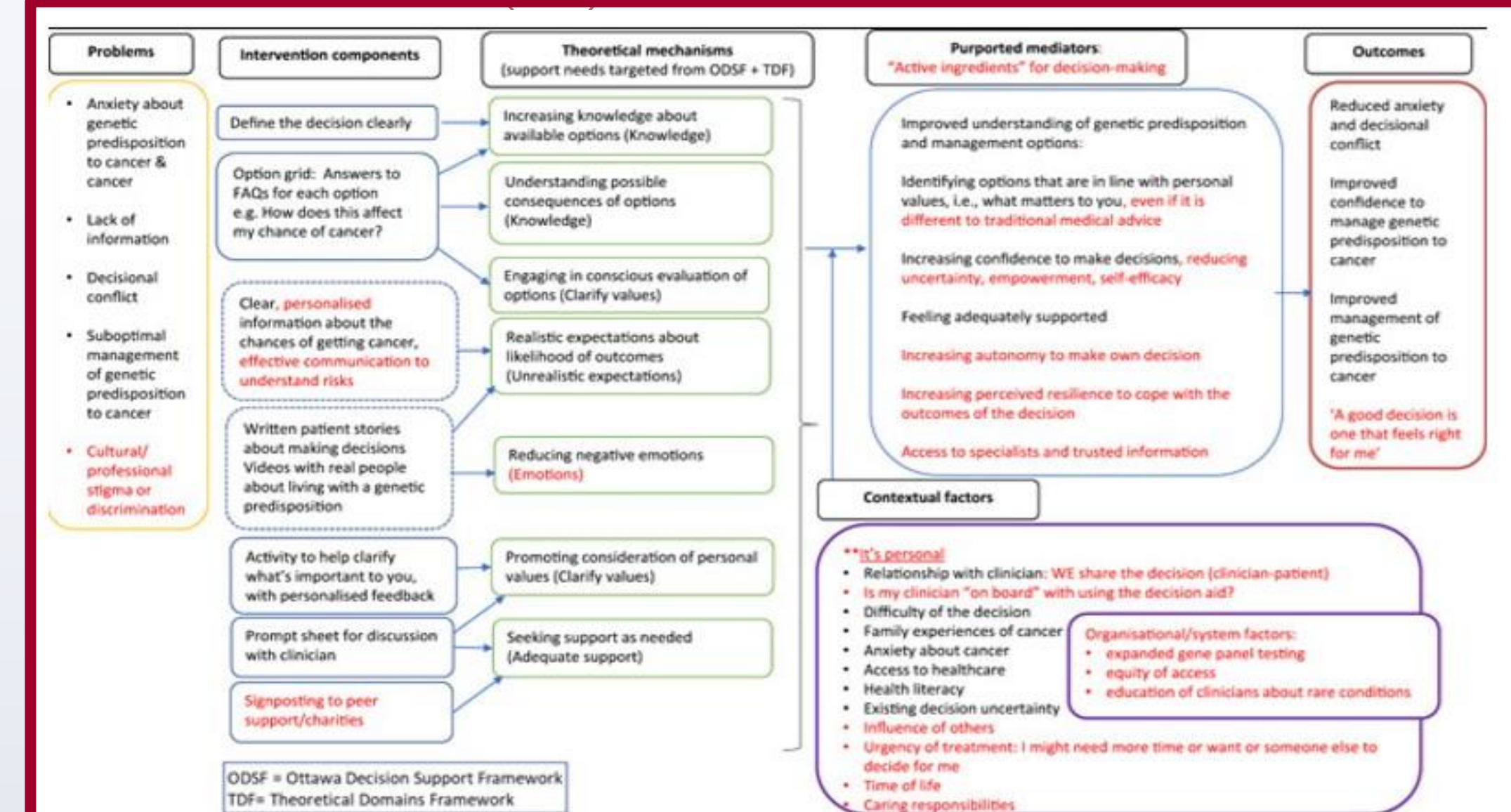


Figure 3. Revised logic model based on output from the workshop, including thematic analysis of patient small group discussions and artwork summary drawing and notes placed on the logic model poster.

Conclusions

Meaningful codesign of PtDA including discussions about the theoretical mechanisms through which they support decision-making has potential to lead to improved patient care through understanding the intricately personal nature of health decisions, and tailoring content and format for holistic care.

Contact details

Kelly Kohut
Lead Consultant Genetic Counsellor and PhD Candidate
k.e.kohut@soton.ac.uk

