

Manchester Cancer Research Centre

Summary of public and clinical feedback for the CYP grant writing period

Overview

Introduction

Throughout the CYP-PRISM writing process, we have spoken to a range of stakeholders who have contributed valuable feedback throughout. The aim is to work with these same core groups continually throughout the lifecycle of the award. There are:

- two **focus groups**, representing people with hereditary gene alterations, charities providing support, and families/carers who are navigating genetics clinics currently
- VoiceIN, an **online feedback tool** which strongly represents young people which will be continually updated
- A **clinical expert group**, giving feedback on proposals.

These groups will experience natural attrition over the course of the grant, so a website has been created to allow people to understand the project more, give a range of ways to get involved, and – if successful – be the primary site to give project updates and host public-facing outcomes. [Developing a risk estimation tool for hereditary cancers in children and young people - Manchester Cancer Research Centre](#)

Focus groups

There are 14 people currently on the circulation group from across all parts of the UK, and focus groups last for 2 hours. For the purposes of this summary, ‘patients’ may refer to the individual themselves, or adults responsible for their care, such as parents, carers, guardians.

We learnt that:

- The broad idea is supported by the group, and they are keen to be involved at several stages
- The idea of linking datasets from varied sources may produce positive results, but anonymity and data protection is key, and must be managed well, especially for very rare cases
- Perspectives on how to present information to patients are different but making sure that information is not hidden and communication is clear is very important
- Signposting patients to more information is important to consider, and has changed how we will disseminate information, introducing new products into the outputs, from clinical training to more lay summaries and wider hereditary genomic education
- What an individual wants to know about their risk score, and possible outcomes, will differ and anything produced will need to reflect this.
- Severity of risk is important to distinguish from probability. This has driven us to changing how we talk about risk from ‘prediction’ to ‘estimation’

This focus group will form the core of the ongoing PPIE group, and we will seek advice, co-design work with this group based on their interests and expertise.

VoiceIN online feedback

VoiceIN is a University of Manchester-designed app which allows PPIE contributors to submit views online based on topics of interest. Between November 2025 and the submission of this bid, we have 176 respondents.

The MCRC is a partnership founded by

We learnt that:

- Broadly, they agree with many of the focus group’s feedback, such as data linkage “I am a complete person, with an incomplete health record”
- The tool allowed a different layer of nuance to the focus group, with more static data points (given the uniformity of the questions)
- Trust among younger people is key – developing a set of resources/tooling around them without their input create mistrust and should be avoided
- Quality information produced in a range of ways is important. This includes different media (including social media), but also point-in-time information which caters to people who want to know different amounts of information
- Providing people with information sources which can be returned to (eg an information pack) will help reduce distress and allow better decision-making for families long-term

Expert clinical group

In parallel with the patient and family contributors, we consulted – via survey – a group of clinicians were offered the chance to give feedback on proposals and practical needs of a risk estimation tool. The following infographic captures those views:

CAN CYP

Clinician Needs & Expectations (Survey Summary)

Design Preferences	Usability Expectations	Patient Communication Needs	Trust, Safety & Credibility
<ul style="list-style-type: none"> Minimal, uncluttered Fast + responsive Clear flow with obvious next steps Immediate access to the tool <p>Do</p> <ul style="list-style-type: none"> Light colour palette Clear navigation / tabs People-focused visuals Simple visual explanations <p>Avoid</p> <ul style="list-style-type: none"> Clutter / excessive text Pop-ups Artificial stock imagery Distressing imagery 	<ul style="list-style-type: none"> Minimal data entry Easy error correction Save progress Works across roles <p>What Drives Adoption</p> <ul style="list-style-type: none"> Quick, intuitive to use Clinically useful outputs Strong evidence base Trusted, validated tool Mobile-friendly <p>Avoid</p> <ul style="list-style-type: none"> Too complex / too many steps High data burden Slow performance Confusing navigation Lack of trust 	<ul style="list-style-type: none"> Printable reports Clear, lay summaries Risk visualisations Comparison to population risk <p>Should be understandable and shareable with</p> <ul style="list-style-type: none"> Clinicians Parents Young people 	<ul style="list-style-type: none"> Clear evidence + references Clinically validated Strong data privacy <p>Transparent about</p> <ul style="list-style-type: none"> Data sources Model limitations

The key finding is that clinicians broadly agree with the PPIE groups on what they need the tool (and associated supports) to deliver for patients.

We will continue to work with clinicians on user design and training for the tool, so that a well-used, robust and helpful tool and wider supports are developed.

Overall learnings: in working consistently with these groups, we can improve the quality of outputs, understand the issues more effectively, and provide a range of supports. This will deliver a well-used, robust research programme which serve patients and families at risk, or living with, hereditary conditions.