

Appendix B: Content development and acceptability of digital information and communication tool

1. Consumers

Themes	Example questions and prompts	Coding
1. Current use of health apps		
	<ul style="list-style-type: none"> • What kind of digital tech do you currently use? What makes them easy to use and what do you avoid? • We describe a health app as any tech that <i>aims to improve your health - such as increasing your weekly exercise, supporting mental health, or helping you lose weight</i> Do you use any tech or apps like this? What types and why? • Do you currently track any lifestyle/wellbeing/health data at the moment? E.g. weight, activity Do you share any of this information with health professionals? Would you like to? • Do you use any digital platform/apps to manage or find help for current health condition (high-risk PVs/Cancer)? 	Useability features Detail of content Barriers and enablers to accessing care Barriers and enablers to use of digital platforms UTAUT ¹ coding <ul style="list-style-type: none"> • Performance expectancy • Effort expectancy • Social influence • Facilitating conditions
2. Identifying key barriers and issues to communication with hospitals (re- access to clinicians at the FCC or management of genetic conditions)		
	<ul style="list-style-type: none"> • Can you tell us about issues that hinder access to support for/or management of your genetic condition including personal management, getting updates, communicating with different specialists? • Outside of your hospital appointments, how do you and your family access information about your health condition? 	Barriers and enablers to accessing care

¹ Venkatesh, V., Thong, J. & Xu, X. (2016). Unified Theory of Acceptance and Use of Technology: A Synthesis and the Road Ahead. *Journal of the Association for Information Systems*, 175, 328-376

- How do you currently communicate about your genetic condition with your family?
- Do you have any suggestions to make it easier to access services at the FCC and manage your current health condition?

3a. (Pre-development) - Expectations and recommendations to develop a digital platform

(Share slide of the envisioned platform)

- From what you have heard– what do you think would be helpful? What should not be included?
- What influence, if any, could such a platform have on how you manage your health condition?
- Thinking about the apps we discussed earlier, are there any essential features in these that we should bring into the design

Barriers and enablers to use of the digital platform

UTAUT coding

- Performance expectancy
- Effort expectancy
- Social influence
- Facilitating conditions

3.b (Trial Phase) - User Experience

(Researchers will show the paper prototype platform to the patients)

- Considering this new platform – what do you think would be helpful? What should not be included?
- How do you think using this mobile app/ digital platform could change how you manage your health condition?
- Can you see three advantages and three barriers to managing your health condition using this platform?
- Can you see three features that this platform should incorporate to support the management of your health condition?

Barriers and enablers to use of paper prototype

UTAUT coding

- Performance expectancy
- Effort expectancy
- Social influence
- Facilitating conditions

4. Additional comments

Do you have any other comments— perhaps the content or the way it could be used?

2. Clinicians

Themes	Example questions	Coding
1. Current ways of working		
	<ul style="list-style-type: none"> How do you currently manage communication with patients (who have a high-risk pathogenic variant) between clinic appointments? What are the main challenges? What would help you manage this communication with your patients better? Are you familiar with any health apps/online information to improve communication with patients? -If yes, can you identify positive and negative points about these? <ul style="list-style-type: none"> If no, Is there a reason why you do not use or direct people to these? Do patients refer to any? With all the health apps available now is there any ongoing data that would be helpful if they could share with you? Is any other data/information that would be helpful to capture from consumers 	Current practice Perceived barriers and enablers to consumers accessing care Perceived barriers and enablers to consumers use of digital platforms UTAUT coding <ul style="list-style-type: none"> Performance expectancy Effort expectancy Social influence Facilitating conditions Useability features of digital platforms Detail of content for platform
2. (Pre-development) - Expectations and recommendations to develop a digital platform		
	(Share slide of the envisioned platform) <ul style="list-style-type: none"> From what you have heard about the proposed content – what influence would this have on your work? How would this fit into your current workflow? 	Barriers and enablers to use of the digital platform UTAUT coding <ul style="list-style-type: none"> Performance expectancy Effort expectancy

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- What impact do you see this platform having on communication with your patients?
 - Who's responsibility should it be to communicate with the patient through this platform? Why
 - what else should be added? What should be left out/avoided
 - How often would you like to be able to send out information? What would this include?
 - What should be the priority areas?
- Social influence
 - Facilitating conditions

2.b (Trial Phase) - User Experience

(Researchers will show the paper prototype platform to the patients)

- Looking at the platform – what do you think would be helpful? What should not be included?
 - Could this platform (as it is now) play a part in communicating with patients between clinic appointments?
 - Could you see yourself using it?
 - Would you trust it?
 - What might prevent you from accessing and using the platform?
 - What might help people to access and using the platform?
- Useability features of paper prototype
 - Detail of content for paper prototype
 - Barriers and enablers to use of paper prototype
 - UTAUT coding
 - Performance expectancy
 - Effort expectancy
 - Social influence
 - Facilitating conditions

4. Additional comments

Do you have any other comments– perhaps the content or the way it could be used?
