

EXPLORING USER-UPTAKE OF DIGITAL CONTACT ACING (D-CT) APPS RACTITIONER Δ GUIDE

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ABOUT OUR LAB

Our research aims to shed insight into the different ways digital technologies are used in disasters and emergencies, the challenges and risks, and benefits and opportunities associated with digital technology use. We seek to provide strategies for guidance, and support efficacy-focused, ethical, low-risk interventions around the world. Our research adopts systems and complex networked perspectives, where we creating understanding through interconnectivity. We engage experts and organizations, both academic and practitioner, across disciplines to evolve research at the intersection of systems to enhance context-driven understanding.

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© 2020 Digital Global Health and Humanitarianism Lab Dahdaleh Institute for Global Health Research (DIGHR) & Disaster & Emergency Management (DEM) EXPLORING USER-UPTAKE IN D-CT APPS

MODULE 9. Recommendations & Future Research

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9.1. Study Overview

9.1.1 Background

At the onset of the COVID-19 pandemic, Digital Contact Tracing (D-CT) emerged as a complement to Manual Contact Tracing (M-CT) to help enhance the capacity of global health systems to track and control the rapid spread and impact of the virus. This innovative approach to contact tracing attracted global attention due to its immense potential to enable faster and more widespread tracing of the virus among symptomatic and asymptomatic infected populations, while also compensating for lower resource availability and physical distancing rules hindering face-to-face care. D-CT apps and interventions from eBracelets to QR codes surged around the world, in the hope that they would make a substantial impact on curbing the global spread of the virus.

To date however, little research exists demonstrating the true impact of these tools. Specifically, despite the widespread implementation of these tools, there is little evidence that shows that D-CT tools (most often apps) do more good than harm. Coupled with issues pertaining to human rights, privacy, efficacy, and digital inclusion, one of the major problems faced with D-CT interventions (mainly those that are voluntary) is the low level of user engagement in these apps – engagement meaning uptake of the app (download and registration), but also using and updating the app, reporting a positive diagnosis through the app, and reacting to an exposure alert received through the app (see our four-stage continuum of D-CT app engagement outlined in Module 1). Looking at uptake of D-CT apps alone, rates vary drastically across different contexts. Ireland and Iceland, for example, have the highest rates at approximately 43% and 40% respectively,¹ while places like Cyprus or South Africa fall below 1%.² And, while many argue that any degree of uptake can make a difference,³ the dominant perception is that all of these rates are insufficient to make a substantial impact on tracing and controlling the virus. In an effort to better characterize the relationship between user engagement and app effectiveness, taking into account there is currently no magic uptake number, research is needed to understand why user-uptake varies between countries.

Through a preliminary literature review and an interdisciplinary workshop, our research team found this problem can be partly attributed to the lack of recognition and understanding of the target users of these apps. Yet, little is known regarding what incentivizes versus inhibits people from downloading these apps around the world, how context plays a role, as well as the association of perceived benefits and risks with

¹Johnson, B. (2020, May 11). Nearly 40% of Icelanders are using a covid app—and it hasn't helped much. MIT Technology Review. Retrieved from <u>https://www.technologyreview.com/2020/05/11/1001541/iceland-rakning-c19-covid-contact-tracing/</u>; Hawkins, L. (2020, September 25). NearForm's privacy-first contact tracing app has high uptake. Healthcare Global. Retrieved January 27, 2021 from <u>https://www.healthcareglobal.com/telehealth-and-covid-19/nearforms-privacy-first-covid-tracking-app-has-high-uptake</u>

²Nortier, C. (2020, October 13). MAVERICK CITIZEN: COVID Alert SA app: The fine balance between public health, privacy and the power of the people. Daily Maverick. Retrieved from <u>https://www.dailymaverick.co.za/article/2020-10-13-covid-alert-sa-app-the-fine-balance-between-public-health-privacy-and-the-power-of-the-people</u>

³O'Neill, P. (2020, June 5). No, coronavirus apps don't need 60% adoption to be effective. MIT Technology Review. Retrieved from <u>https://www.technologyreview.com/2020/06/05/1002775/covid-apps-effective-at-less-than-60-percent-download/</u>

user engagement. As part of <u>The Digital Global Health and Humanitarianism (DGHH) Lab's</u> larger study on the factors impact user-engagement across the four-stage continuum, this study focuses specifically on trying to address this gap by exploring stage 1 – user-uptake of D-CT apps – across various countries.

9.1.2 Methodology

This research asks the following research question:

Why is there higher user-uptake of D-CT apps in some countries over others?

This question is addressed with the following sub-questions:

- i. How does uptake vary across contexts?
- ii. What factors influence uptake across contexts?
- iii. How does risk-benefit perception influence uptake?

To answer these questions, we first established the scope of our research. Our focus is on user-uptake of D-CT apps (the most prevalent form of D-CT interventions worldwide) implemented by governments around the world at the national level, that are voluntary to download, and primarily decentralized in their data collection (a measure that mitigates privacy and human rights concerns that are widely recognized as a factor that deters app engagement).⁴ Second, a multiple case study approach was used to generate country-specific understanding of user-uptake of D-CT apps and address our research questions. Cases selected include: Ireland, Cyprus, Ireland, Scotland, and South Africa. Data was collected through interdisciplinary workshops, interviews, and meta-analysis of existing peer-reviewed and grey literature. Research findings were analyzed through a systems-approach based on Bronfennbrenner's ecological systems theory to identify varied contextual factors that influence uptake (through a risk-benefit lens).⁵ Bronfennbrenner's theory aims to define user behaviour as a product of intrinsic and extrinsic interactions and influences with different levels in their surrounding system: individual (micro-level), community (meso-level), and system (macro-level). Research findings are presented through a series of modules (identified in Section 9.1.4 below) through an introduction to D-CT and user-uptake; case study; systems analysis of factors identified that influence uptake; and recommendations and future research. For a more detailed overview of our research approach, please see the full methodology.

9.1.3 Overview of Cases & Factors Identified

As shown through the five case studies, **eight factors** that can explain uptake across the individual (micro), community (meso), and system (macro) level dimensions have been identified. Each factor is explained below.

⁴Lomas, N. (2020, April 6). EU privacy experts push a decentralized approach to COVID-19 contacts tracing. TechCrunch. Retrieved from <u>https://techcrunch.com/2020/04/06/eu-privacy-experts-push-a-decentralized-approach-to-covid-19-contacts-tracing/</u>

⁵ Wikipedia Contributors. (2019, February 10). Ecological systems theory. Wikipedia; Wikimedia Foundation. Retrieved from <u>https://en.wikipedia.org/wiki/Ecological systems theory</u>

- Perceptions of Data Collection & Management how people perceive actual data collection and management as it relates to privacy and trust; and individual understanding of privacy and security (independent of actual privacy and security measures built into D-CT apps).
- 2. **Sense of Community** the level of shared trust, shared identity, sense of duty, and/or communitarian values individuals have in relation to their community; and the strength of ties/connectedness individuals have with each other.
- 3. **Communications & Misinformation** the timeliness, transparency, method, and nature of information provided to the nation alongside the prevalence, spread, and control of misinformation.
- 4. **Accessibility & Inclusion** the degree to which D-CT apps are equally accessible to, usable for, and inclusive of, the entire population, as well as the level of discrimination and marginalization that results from interventions that fail to account for the digital divide or socially vulnerable populations.
- Trust in Public/Private Institutions the widespread level of trust and faith in public institutions (e.g. government, response agencies) and private institutions (e.g. internet corporations like Google, Apple, as well as the developers of D-CT apps).
- 6. **Policy & Governance** the use of, and adherence to, policies and governance mechanisms that regulate the development, implementation, and use of the app.
- 7. **Response Infrastructure** the ability of the health infrastructure alongside the first-line response and emergency management infrastructure to manage the COVID-19 pandemic (such as access to testing, and the capacity to respond to and treat the virus).
- 8. **Digital Capability** the ability of D-CT apps to effectively and efficiently serve their purpose and facilitate the management of the pandemic.

9.1.4 Practitioner Guide Outline

The findings of this study are presented through eleven modules including:

Module 0 – Executive Summary
Module 0 - Methodology
Module 1 - Digital Contact Tracing (D-CT) and User-Uptake: A Primer
Module 2 - Case Study: Iceland
Module 3 - Case Study: Cyprus
Module 4 - Case Study: Ireland
Module 5 - Case Study: Scotland
Module 6 - Case Study: South Africa
Module 7 - Analysis of User-Uptake Factors: Individual- & Community-Level Influences
Module 8 - Analysis of User-Uptake Factors: System-Level Influences
Module 9 - Recommendations & Future Research

9.2. Module Overview

This module first aims to provide high-level recommendations for implementers ranging from decisionmakers in government to app developers to humanitarian responders, on reasons why app-uptake may vary across contexts and how risks versus benefits should be considered in efforts to enhance uptake. Second, this module aims to identify areas of future research that are worth pursuing to gain more understanding of the risks and benefits towards users. Recommendations are provided through five main challenges identified in the research which are linked to user-uptake. Each challenge is described and recommendations specific to that challenge are provided. Each challenge is coupled with a visual depiction of how each recommendation addresses the eight factors influencing user-uptake. Future research is described specific to user-uptake, the four stages of user engagement, and the context of D-CT study in general.

9.3. Recommendations

Through a synthesis of research findings, five main challenges consistently emerged across case studies and in the broader literature that may increase the perception of risk of D-CT apps over benefit, thereby ultimately leading to lowered uptake. Described in depth below, these challenges are associated with fears regarding personal data collection in connection with short-term and long-term surveillance, overriding misconceptions of privacy, disproportionately impacted communities, poor perceptions of D-CT app effectiveness, and digital capability hurdles. A series of recommendations are provided below to address each of these challenges identified in our research which, if pursued, may mitigate the risks and optimize the benefits of D-CT apps to improve app-uptake. Table 9.0 provides a high-level overview of these recommendations and how they can address the eight factors identified in this study that influence user-uptake of D-CT apps.

	MICRO	М	ESO		-	MACRO		
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
RECOMMENDATIONS	Perceptions of Data	Sense of Community	Communications & Misinformation	Accessibility & Inclusion	Trust in Government	Policy & Governance	Response Infrastructure	Digital Capability
CHALLENGE 1: Fears of immediate an								
Build Open & Transparent Communication between Government Officials and Citizens and Residents								
Ensure a clear data deletion period and D-CT surveillance end date								
Build and/or Leverage "Trust Building" Relationships								
Make D-CT Apps Open-Source								
Employ Ethical Hacking as a Proactive Cybersecurity Strategy								
CHALLENGE 2. Privacy perceptions n	nay override p	rivacy-by-des	sign principles					
Increase education & awareness on data privacy								
Encourage an Apolitical, Science-Led Response								
Create a National Hotline to Report on Misuse/Scams associated with D-CT Apps								
Ensure Open & Transparent Data Collection & Data Management Process								
CHALLENGE 3: Some communities an	e disproportio	onately affect	ed by and/or ex	cluded from [)-CT applicati	ons/measures	5	
Build Perceptions of Working Together & Highlight Shared Values		\checkmark						
Understand and Prevent/Mitigate Differential Impacts		\checkmark						
Expand Media Coverage With More Inclusive Social Media Campaign		\checkmark						
Build Multilingual Functionality		\checkmark	\checkmark					
Ensure Compliance with Accessibility Standards								
Ensure Equal Incentives		\checkmark						
CHALLENGE 4: Perceptions of D-CT a	app effectiven	ess are poor						
Build, Strengthen & Communicate the Relationship Between Manual and Digital Contact Tracing								
Strive to limit false positives; strive to better embed incubation and infection risk into D-CT software								
Minimize Digital Glitches			\checkmark					
Build Communication Channels Between App-Users and App Developers								
Build App Functionality			\checkmark					
CHALLENGE 5: Digital limitations inhi	ibit people fro	m downloadi	ng D-CT apps					
Minimize Technical & Connectivity Requirements								
Make App-Installation and App-Use Tutorials That are Brief								
Supply Individuals with Mobile Phones or Alternative Technologies to enable Participation								

Table 9.0: High Level Overview of Recommendations and Corresponding Factors Addressed

9.3.1. CHALLENGE 1: Fears of immediate and future surveillance, and alternative uses of personal data

Since D-CT apps rely on the use of personal data, fears around the potential of immediate and future surveillance and questionable data practices impact user-uptake. Without adequate safeguards, transparent communication around data storage and use, and robust risk mitigation strategies, sensitive personal data may be compromised leading to potential present and future surveillance risks as well as risks to human rights in terms of privacy, autonomy, among others. The recommendations below may reduce the risk users perceive and/or optimize the benefits users perceive in downloading and using D-CT apps by addressing the factors highlighted in Table 9.1.

	MICRO	M	ESO			MACRO		
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8
RECOMMENDATIONS	Perceptions of Data	Sense of Community	Communications & Misinformation	Accessibility & Inclusion	Trust in Government	Policy & Governance	Response Infrastructure	Digital Capability
CHALLENGE 1: Fears of immediate a	nd future surv	eillance, and	alternative uses	s of personal o	data			
Build Open & Transparent Communication between Government Officials and Citizens and Residents			\checkmark					
Ensure a clear data deletion period and D-CT surveillance end date			\checkmark					
Build and/or Leverage "Trust Building" Relationships								
Make D-CT Apps Open-Source								
Employ Ethical Hacking as a Proactive Cybersecurity Strategy								

Table 9.1.0.: Challenge 1 Recommendations and Corresponding Factors Addressed

9.3.1.1. Build Open & Transparent Communication between Government Officials and Citizens and Residents

Open and transparent communication between government officials and citizens and residents can address all eight factors across the individual (micro), community (meso), and system (macro) levels including: 1) Perceptions around Data Collection & Management; 2) Sense of Community; 3) Communications & Misinformation; 4) Accessibility & Inclusion; 5) Trust in Government; 6) Policy & Governance; 7) Response Infrastructure; and 8) Digital Capability. For instance, early, clear, and effective communication practices about D-CT app data protection, sharing, and privacy protections that also are reinforced through open communications policies may further build trust between government officials and citizens and residents and address the latter groups' perceptions of data collection and management. Alternatively, if communication measures account for the country's context so as to leverage people's values, address their concerns, and communicate in a way that is accessible to as many people as possible, it can build a sense of community, be inclusive, as well as address any misinformation. As a final example, transparent communication about uncertainties may increase public understanding and perception of evolving government strategies relating to the COVID-19 response infrastructure's capacity. High levels of approval of the government's response may increase willingness to comply with directives such as downloading contact tracing apps, thereby also actually improving the COVID-19 response. Similarly, having strong policies that regulate communicating a D-CT app's current glitches and expected updates to fix the problem also may help navigate users' perceptions about the app's digital capability and encourage continued user engagement.

9.3.1.2. Ensure a Clear Data-Deletion and D-CT Surveillance Period End-Date

Introducing limits on use of data and storage times while also providing privacy policies in plain language can address four of the eight factors: 1) Perceptions of Data Collection & Management; 2) Communications & Misinformation; 3) Trust in Government; and 4) Policy & Governance. Clearly defined policy surrounding data deletion and surveillance that is shared openly with the public can build trust in government and perceptions around data collection & management. Clearly and transparently communicating these policies similarly will address these factors. For example, the privacy policy of Iceland's *Rakning C-19* is written in simple language, making it accessible to many regardless of their level of education. Additionally, it is explicitly communicated that the user's data is stored on their phone for only 14 days and that further consent is required to share their data with a contact tracing team if they test positive for COVID-19. If shared, their data is deleted from the contact tracing team's database in 14 days. This clear delineation of who has access to the data, for how long, and that their data will not be repurposed is essential to increase the confidence of users by reducing fears of mission creep (the risk of data being used for more than its original intended purpose), and reassuring users that privacy infringements will be avoided.⁶ These have been suggested as important prerequisites for wide-spread adoption of voluntary D-CT apps.

9.3.1.3. Build and/or Leverage Trust Building Relationships

Establishing trust-building relationships (relationships with external entities that are perceived favourably and trustworthy by the general public) – particularly with developers – can address three factors: 1) Perceptions of Data Collection & Management; 2) Trust in Government; 3) and Policy & Governance. With the Google Apple Exposure Notification (GAEN) Application Programming Interface (API) dominating D-CT apps around the world, the partnership between governments and Google and Apple has raised mixed emotions in terms of privacy perception. On one hand, while Google and Apple are widely recognized for their products and services worldwide (already having gained the trust of millions), the space in which they operate is highly unregulated making it difficult to pinpoint specific instances of privacy violations. There is substantial evidence however, of cases where these businesses have breached privacy rights.⁷ Furthermore, the use of Amazon Web Services to store data collected through some D-CT apps has resulted in users expressing concerns regarding the storage of their personal data on servers that are connected to Amazon and also may be outside of their country of origin. Risks may range from alternate liability risks⁸ to loss of control over the use and repurposing of their data beyond state borders. Meanwhile, Ireland's approach to working with Nearform and the Linux Foundation Public Health (both open-source software initiatives, explained further in Section 9.3.1.4) appears to have reflected positively on the perception of the app. The success of this initiative has led to Nearform implementing their app in

https://www.cnbc.com/2020/12/10/google-and-amazon-fined-for-cookies-breach-by-french-privacy-regulator.html

⁶ Klar, R., & Lanzerath, D. (2020). The ethics of COVID-19 tracking apps – challenges and voluntariness. *Research Ethics*, 16(3-4), 174701612094362. <u>https://doi.org/10.1177/1747016120943622</u>

 ⁷ Bogost, I. (2020, Jan 31). Apple's Empty Grandstanding About Privacy. The Atlantic. Retrieved from <u>https://www.theatlantic.com/technology/archive/2019/01/apples-hypocritical-defense-data-privacy/581680/</u>; Shead, S. (2020, Dec 10). Google and Amazon fined for cookies breach by French privacy regulator. CNBC. Retrieved from

⁸ Robson, E. S. (2012). Responding to liability: evaluating and reducing tort liability for digital volunteers. Woodrow Wilson International Center for Scholars, Washington, DC. Retrieved from <u>https://www.wilsoncenter.org/publication/responding-to-liability-</u> evaluating-and-reducing-tort-liability-for-digital-volunteers

other countries such as Germany and Italy.⁹ There remains however, an accountability gap when it comes to the development of third-party apps by the private sector, nor is there sufficient governance around the development and deployment of D-CT apps across contexts, particularly where privacy and other fundamental rights protections vary greatly from state to state.¹⁰ In order for D-CT apps to be legally compliant in many jurisdictions, and contribute to building trust perception in governments that leverage these relationships, developers will at minimum have to prove that they are able to implement robust and comprehensive data protection measures at the highest standard that fully adhere to international standards and comply with regional and national data protection and privacy laws (where available and applicable).

9.3.1.4. Make D-CT Apps Open-Source

From the case studies, countries that adopted an open-source backend to their D-CT apps exhibited higher uptake, likely linked to the four factors it addresses: 1) Perceptions of Data Collection & Management; 2) Trust in Government; 3) Policy & Governance; and 4) Digital Capability. Ireland, for example, partnered with Nearform (a privacy centric developer of open-source solutions) and donated their app to the Linux Foundation Public Health (an open-source software initiative). Open-sourced code can be publicly checked for potential security flaws and reveal issues within the code itself. These features can improve trust in government, perceptions around privacy, as well as digital capability, all of which may influence app-uptake.¹¹ Though many of the benefits derived from making code public are not understood or known by most users, open source technology has widespread support within the development community, and these opinions and beliefs of experts find their way into the public narrative via social media, blogs, and articles. Building the requirement of having D-CT apps open-source into policy so that open-source protocols are adhered to may further address these factors, mitigating the perceived risks and optimizing the perceived benefits of app-uptake.

9.3.1.5. Employ Ethical Hacking as a Proactive Cybersecurity Strategy

Employing ethical hacking can address a multitude of the individual (micro), community (meso), and system (macro) level factors including: 1) Perceptions of Data Collection & Management; 2) Communications & Misinformation; 3) Trust in Government; and 4) Policy & Governance. Although governments may take measures to minimize varied cybersecurity risks, like making their software open-source discussed above, there is inherent risk to privacy and security with any digital products. As such, developers and implementers should take a proactive and innovative approach to cybersecurity, rather than a reactive approach. Ethical hacking is one such proactive cybersecurity strategy that allows private, public, and non-governmental organizations to perform penetration testing in the form of web application and infrastructure penetration testing, mobile device and mobile app penetration testing, and red teaming.¹² As per cybersecurity consultants, penetration testing minimizes risk by showing

⁹ Gorey, C. (2020, October 19). Irish Covid Tracker app now linked with apps from Germany and Italy. Silicon Republic. Retrieved from <u>https://www.siliconrepublic.com/enterprise/irish-covid-tracker-app-interlinked-germany-italy</u>

¹⁰ See also <u>https://www.article19.org/resources/coronavirus-tracking-apps-and-human-rights-what-you-need-to-know/</u>

¹¹ Hoepman, J. H., & Jacobs, B. (2007). Increased security through open source. *Communications of the ACM*, 50(1), 79-83.

¹² Nicholson, S. (2019). How ethical hacking can protect organisations from a greater threat. *Computer Fraud & Security*, 2019(5), 15–19. <u>https://doi.org/10.1016/s1361-3723(19)30054-5</u>

organizations how malicious actors would gain "access rights to a system" or app including those "that are created specifically for mobile devices such as apps on the iOS and Android platforms."¹³ While some apps studied are not utilizing this ethical hacking approach (e.g. Cyprus' *CovTracer*), governments, technology corporations, and banks across the globe have adopted this solution to protect their digital architecture and network infrastructure. Leveraging this solution, communicating that this step has been taken to protect data and people's privacy, and building such proactive cybersecurity strategies into policies may improve perceptions relating to data privacy as well as trust in the government.

9.3.2. CHALLENGE 2. Privacy perceptions may override privacy-bydesign principles

Beyond the actual risks associated with D-CT apps designed with lower privacy and security protocols (from countries that bypass data protection safeguards to countries with questionable surveillance approaches), our research shows that lack of comprehension surrounding app functionality and misunderstanding the privacy safeguards that are in place are also quite common. This finding implies that, in some cases, following privacy-by-design principles may not be enough to change perceptions around privacy. These interpretations – combined with the lack of user education around the app and its privacy-preserving components alongside barriers to providing that education – have been identified as important factors hindering uptake. Also, as demonstrated in Figure 9.1.0, there is a disconnect between app-use and claimed privacy needs.



Figure 9.1.0. Comparison of permissions required between Facebook, Instagram, Tinder and Canada's COVID Alert App

¹³ Ibid.

Comparing apps like the *COVID Alert* app in Canada to some of the most popular social apps in use today (e.g. TikTok, Tinder, Twitter, etc.), the *COVID Alert* app collects far less data and has more privacy-preserving components built into the app. Yet, the above social media platforms have millions of users.¹⁴ Generally, user research suggests people are willing to forfeit privacy in exchange for services. Yet, this discrepancy in uptake of contact tracing tools highlights that perhaps privacy is not the prominent factor in determining uptake and should not be the sole focus of developers, implementers, and regulators. The following recommendations below take this discrepancy into consideration and address the Perceptions of Data Collection & Management factor as well as a variety of other factors as outlined in Table 9.2.0.

	MICRO	М	ESO			MACRO	o		
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	
RECOMMENDATIONS	Perceptions of Data	Sense of Community	Communications & Misinformation	Accessibility & Inclusion	Trust in Government	Policy & Governance	Response Infrastructure	Digital Capability	
CHALLENGE 2. Privacy perceptions	may override	privacy-by-d	esign principle	s					
Increase education & awareness on data privacy									
Encourage an Apolitical, Science-Led Response			\checkmark						
Create a National Hotline to Report on Misuse/Scams associated with D-CT Apps									
Ensure Open & Transparent Data Collection & Data Management Process									

 Table 9.2.0: Challenge 2 Recommendations and Corresponding Factors Addressed

9.3.2.1. Increase Education & Awareness on Data Privacy

Increasing education and awareness on D-CT data privacy may address six of the eight factors including: 1) Perceptions of Data Collection & Management; 2) Communications & Misinformation; 3) Accessibility & Inclusion; 4) Trust in Government; 5) Policy & Governance; and 6) Digital Capability. As described above and throughout the case studies, even when countries adopt rigorous privacy-preserving mechanisms and exhibit high compliance with privacy regulations, many users still lack full comprehension of privacy and security in the general sense of how it relates to D-CT apps. Consequently, the need exists to help users better understand the concept of privacy and how it relates to D-CT apps. Once again using Iceland's Rakning C-19 app as an example, the easy-to-understand privacy policies were made accessible to users in the early stages of the pandemic. In combination with clear and transparent communications regarding how data was stored, shared, and used with contact tracers, these education and awareness campaigns were inclusive and likely strengthened trust in government as it helped to make the purpose and intentions of the app more clear. Meanwhile, the shift seen in many countries from using the phrase 'digital contact tracing apps' to using 'exposure notification apps' can be interpreted as a linguistic reframing measure to shift people's perceptions of D-CT apps as a means for surveillance to a means of participation in monitoring and controlling the spread of the virus. This reframining can ultimately be considered a trust building measure.

¹⁴ Mello, J. (2020, October 27). Social Media Companies Top Data Grabber List. Tech News World. Retrieved from <u>https://www.technewsworld.com/story/86897.html</u>

9.3.2.2. Encourage an Apolitical, Science-Led Response

Encouraging an apolitical, science-led response is a recommendation that addresses four of the eight factors: 1) Perceptions of Data Collection & Management; 2) Communications & Misinformation; 3) Trust in Government; and 4) Response Infrastructure. Across case studies, many governments not only built task-forces or advisory groups encompassing epidemiologists, researchers, and experts in the field of pandemic management, but also prioritized apolitical messaging with the public. As reported in Module 8, Icelandic authorities had a 96% approval rating from citizens and residents regarding the country's COVID-19 response.¹⁵ Research attributes the approval rating to the government's reliance on scientific expertise during the pandemic,¹⁶ holding daily press briefings framed as just the facts "no politics and no politicians getting in the way."¹⁷ Conversely, South Africa's science-based response inherently was mixed with political ongoings which likely further exacerbated distrust in the government. Study shows that apolitical, science-led approach that is heavily exhibited through public communications and subsequent action may encourage app-uptake by promoting trust in government, improving perception of the country's COVID-19 response infrastructure, and even influencing perceptions of data and privacy as it relates to D-CT apps and the necessity of them within a scientifically-backed COVID-19 response.

9.3.2.3. Create a National Hotline to Report on Misuse/Scams associated with D-CT Apps

Creating a national hotline to report misinformation on, scams relating to, or misuse of, D-CT apps can address five factors across the individual (micro), community (meso), and system (macro) levels. These factors include: 1) Perception of Data Collection & Management; 2) Communications & Misinformation; 3) Accessibility & Inclusion; 4) Trust in Government; and 5) Response Infrastructure. In South Africa, while not specifically a national hotline designated for COVID-19 misinformation/scams, some citizens and residents used the Real411 platform to report cases of misinformation in relation to the country's D-CT app and COVID-19.¹⁸ A national hotline would be beneficial in situations like those seen in Scotland where scammers acted as government officials affiliated with the *Protect Scotland* app to gain personal information. Addressing misinformation surrounding, and the misuse of, D-CT apps through such safeguard mechanisms may not only help facilitate accurate information being shared, but may improve trust in the government because the institution, for instance, is not being impersonated by scammers. Furthermore, a hotline may help assure citizens and residents that the government is taking action to protect privacy, thereby improving perceptions surrounding data collection and management. Similarly, it can minimize the risk of malicious actors targeting vulnerable populations which can improve a D-CT apps

¹⁵ Askham, P. (2020, April 21). COVID-19 in Iceland: Tenth death, new government package announced. Grapevine. <u>https://grapevine.is/news/2020/04/21/covid-19-in-iceland-tenth-death-new-government-package-announced/</u>.

¹⁶ Hjelmgaard, K. (2020, April 10). Iceland has tested more of its population for coronavirus than anywhere else. Here's what it learned. *USA Today*. Retrieved from <u>https://www.usatoday.com/story/news/world/2020/04/10/coronavirus-covid-19-small-nations-iceland-big-data/2959797001/</u>.

¹⁷ Kolbert, E. (2020, June 1). How Iceland beat the Coronavirus. *The New Yorker*.

https://www.newyorker.com/magazine/2020/06/08/how-iceland-beat-the-coronavirus

¹⁸ Smith, T., & Bird, W. (2020, September 20). OP-ED: Disinformation in a time of Covid-19: Weekly trends in South Africa. Daily Maverick. Retrieved from <u>https://www.dailymaverick.co.za/article/2020-09-20-disinformation-in-a-time-of-covid-19-weekly-trends-in-south-africa-10/</u>

inclusivity. Finally, perceptions surrounding the response infrastructure may be positively influenced by improving the efficacy of the COVID-19 response through a national hotline.

9.3.2.4. Ensure Open & Transparent Data Collection & Data Management Process

An open and transparent data collection and management process can address five factors including: 1) Perceptions of Data Collection & Management; 2) Communications & Misinformation; 3) Accessibility & Inclusion; 4) Trust in Government; and 5) Policy & Governance. Perceptions of data collection and management may be positively influenced through centering transparency in data collection and management processes alongside subsequent communications in the development and deployment of D-CT. Focus should be placed on communicating the purpose of the app and the intention behind data collection. Furthermore, to avoid mission creep (defined in Section 9.3.1.2), apps should only collect data that is absolutely necessary. To combat mission creep, regulations against data sharing across public entities must contain a commitment to no data sharing with law enforcement, including any and all health data or location tracking data. Strict regulation of third-party access also must be managed. If third party access is essential, a potential risk minimizing intervention could be allowing users to see which organizations are accessing their data in real time. Users can then be provided an opt-out option for certain third-party organizations without which the app's functionality would not be compromised. This would give users a sense of security and control over where and when their data is accessed and would have full knowledge of organizations privy to their information. There should also be a robust chain of custody agreements for data passed between government, industry, and researchers, which includes a process to delete data, in compliance with various regional mechanisms like the General Data Protection Regulation (GDPR), if applicable. The protection of data sovereignty must ensure that all data are subject to domestic and international laws and governance structures and that there are mechanisms of judicial oversight of government, industry and researchers developing and deploying D-CT apps. Any meaningful oversight also must include a commitment to corporate accountability if data is misused, stolen, or sold. Not only do these measures strengthen policy and governance surrounding data collection and management processes and perceptions surrounding data collection and management, but will likely increase trust in government in relation to these processes. Furthermore, by strengthening the protections around data collection and management processes, certain vulnerable or marginalized communities may feel more confident in using the government's D-CT app, thereby improving accessibility and inclusion. It is important to note that these open and transparent processes also must be communicated in an inclusive and clear manner, as iterated in Section 9.3.1.1, 9.3.1.2, 9.3.2.1, 9.3.3.2, and 9.3.3.3.

9.3.3. CHALLENGE 3: Some communities are disproportionately affected by and/or excluded from D-CT apps/measures

As highlighted in Modules 7 & 8, there are some communities that are disproportionately affected by COVID-19 and/or excluded from D-CT apps, such as the elderly or the visually impaired. Additionally, there also are certain communities that have historically been at the forefront of state surveillance. It is particularly within these communities that privacy, data protection risks, and other rights infringements must be considered contextually, considering these communities' experiences at the intersection of various factors such as race, ability to access and adequately use mobile smartphones, age, social location,

socioeconomic status, and other characteristics that may impact a user's willingness to engage with D-CT apps. This contextual analysis should inform any development and deployment of D-CT apps to be human rights compliant and inclusive, particularly for communities disproportionately impacted by COVID-19 yet reticent to engage in tracking technologies due to histories of surveillance and discrimination. The recommendations in this section focus on improving accessibility and inclusion alongside building a sense of community while also addressing other factors as outlined in Table 9.3.0.

	MICRO	М	ESO	MACRO					
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	
RECOMMENDATIONS	Perceptions of Data	Sense of Community	Communications & Misinformation	Accessibility & Inclusion	Trust in Government	Policy & Governance	Response Infrastructure	Digital Capability	
CHALLENGE 3: Some communities are disproportionately affected by and/or excluded from D-CT applications/measures									
Build Perceptions of Working Together & Highlight Shared Values		\checkmark							
Understand and Prevent/Mitigate Differential Impacts		\checkmark							
Expand Media Coverage With More Inclusive Social Media Campaign		\checkmark							
Build Multilingual Functionality		\checkmark							
Ensure Compliance with Accessibility Standards		\checkmark							
Ensure Equal Incentives		\checkmark				Image: A start of the start			

Table 9.3.0: Challenge 3 Recommendations and Corresponding Factors Addressed

9.3.3.1. Build Perceptions of Working Together & Highlight Shared Values

Building perceptions of working together & highlighting shared values may address three factors: 1) Sense of Community; 2) Communications & Misinformation; and 3) Accessibility & Inclusion. As seen in the Iceland and Ireland case studies, both countries' governments leveraged pre-existing communitarian values – such as asking people to "be a strong link in the chain" – to encourage app-uptake. It is thought that promoting perceptions of working together may influence individuals to download the app. It should be noted though, that in the case of South Africa, promoting communitarian values seemed not to be as effective because the sense of community is quite low. Therefore, it seems that communitarian values need to be pre-existing in order for building perceptions of working together to be effective. In saying that, should South Africa's government highlight other shared values, that tactic may be effective in influencing user-uptake. Building perceptions of working together and highlighting shared values through communications strategies very clearly addresses the sense of community and communications & misinformation factors. Furthermore, in building a sense of community there seems to be a component of strengthening inclusivity.

9.3.3.2. Understand and Prevent/Mitigate Differential Impacts

Understanding and preventing or mitigating differential impacts can address six factors: 1) Perceptions of Data Collection & Management; 2) Sense of Community; 3) Communications & Misinformation; 4) Accessibility & Inclusion; 5) Trust in Government; and 6) Policy & Governance. It is important to recognize and mitigate the differential impacts of D-CT apps on marginalized groups such as racialized communities, sex workers, LGBTQ2S+ persons, persons facing precarious housing situations, Indigenous groups, persons with precarious immigration status, and elderly populations, among others. As an example, Cyprus is facing an issue where its elderly population is unable to engage with the D-CT app due

to digital literacy amongst other factors.¹⁹ Groups that have historically faced surveillance and subsequent discrimination also require specific attention to understand and prevent or mitigate the differential impacts of D-CT apps. This is because these communities will be more reticent to engage in state-sanctioned tracking apps even though these groups may be at greater risks associated with COVID-19. As such, context-specific messaging and interventions, as well as robust privacy-protecting and anti-discrimination mechanisms, must be part of every D-CT app that is developed and deployed to ensure human rights compliance as well as to encourage user-uptake from marginalized communities. For instance, in the Interim Report released on *Protect Scotland*, the component looking at gender reassignment pointed out that security and confidentiality were top priorities in the community not just for the *Protect Scotland* app but also for the wider Test and Protect health initiative.²⁰

Inclusive, accessible, and contextualized messaging is important to regulate the perceptions of data collection and management that can be particularly negative as a consequence of these populations' previous experiences. Considering these communities within D-CT app development and implementation strategies can improve the accessibility of D-CT apps to a wider audience, be increasingly inclusive, and strengthen the sense of community within these communities as well as across the nation. Revisiting the elderly for example, taking steps to mitigate the disproportionate impacts that may result from not being able to download and/or use the app – such as by providing wearable tokens that require significantly less digital literacy – D-CT becomes more inclusive. Facilitating the above actions, particularly implementing robust privacy-protecting and anti-discrimination policies, may start to strengthen these populations' trust towards the government.

9.93.3.3. Expand Media Coverage with More Inclusive Social Media Campaign

Expanding media coverage with more inclusive social media campaigning can address: 1) Sense of Community; 2) Communications & Misinformation; and 3) Accessibility & Inclusion. The Interim Report released on *Protect Scotland* outlined a communications campaign plan to reach 90% of the Scottish population across a four-week period though a variety of mediums including television and press.²¹ The 90% reach is impressive, but could also be reintroduced to target specific communities to be even more inclusive. Other countries can also learn from Scotland's strategy to facilitate inclusive communications that is both more accessible to various populations but also inclusive of populations that are often marginalized. This recommendation directly focuses on improving accessibility to accurate information and is thereby expanding who is included in D-CT app development, implementation, and communications as well as continuing to build a sense of community.

9.3.3.4. Build Multilingual Functionality

Building multilingual functionality in D-CT apps can address three factors: 1) Sense of Community; 2) Communications & Misinformation; and 3) Accessibility & Inclusion. In the case studies, countries that

¹⁹ Browne, B. (2020, November 8). Tech push leaving the elderly behind. *CyprusMai*l. Retrieved from <u>https://cyprus-mail.com/2020/11/08/tech-push-leaving-the-elderly-behind/</u>

²⁰ Interim National Equality Impact Assessment Protect Scotland App. (2020). Digital Health & Care Scotland. Retrieved from <u>https://www.protect.scot/resources/docs/EQIA-17-september-2020.pdf</u>

²¹ Ibid.

offered their D-CT apps in more languages were also those with higher uptake. For example, Iceland (high uptake) offered their app in eight languages²² while with 11 official languages South Africa (low uptake) has, to date, only implemented their app in English.²³ Research from Scotland investigating disability suggests further consideration is required for those in the deaf and blind community, those who use British Sign Language, and people with learning disabilities.²⁴ In building multilingual functionality, D-CT becomes accessible to more people and subsequently can contribute to help bridge and build a deeper sense of community if all groups are included. Furthermore, since some D-CT apps also share important pandemic-related information, distributing accurate information in multiple languages increases accessibility as well as combats misinformation.

9.3.3.5. Ensure Compliance with Accessibility Standards

Ensuring compliance with accessibility standards can address three of the eight factors: 1) Sense of Community; 2) Communications & Misinformation; and 3) Accessibility & Inclusion. Although some countries made efforts to include accessibility features into their app designs, e.g. Ireland offering app instruction in sign language and Scotland ensuring the app is compatible with Apple and Google screen readers, it was difficult to identify how apps leverage smartphone assistive technologies. This finding highlights the importance of identifying areas where D-CT apps do not meet accessibility standards and to take steps to ensure that they comply with these standards. This recommendation will improve accessibility of the D-CT app – and subsequently improve the sense of community – but also improve accessibility to any information the app provides, thereby strengthening the sharing of accurate information.

9.3.3.6. Ensure Equal Incentives

Ensuring equal incentives will address four factors: 1) Perceptions of Data Collection & Management; 2) Sense of Community; 3) Accessibility & Inclusion; 4) Policy & Governance; and 5) Response Infrastructure. Discussions surrounding the benefits of D-CT apps ultimately refer to what factors incentivizes users to download and use an app. For instance, across all apps, the benefit accrued to the user is that they can be notified if exposed to COVID-19. Subsequently, they are provided with information on next steps to take, such as getting tested and/or being treated. Yet, this is only truly a benefit in countries with equitable access to healthcare. For example, in South Africa, where healthcare is not equally accessible and the healthcare system is overburdened and under-resourced, the incentive to use a D-CT app diminishes because users often cannot fulfill the next steps after receiving an exposure notification. Beyond providing testing and treatment, mechanisms must exist to protect personal data and identities while also being robust and secure enough to prevent the risk of a positive test not being leaked to their surrounding community. In some communities, leaking a positive COVID-19 test result poses severe stigmatization risk. In New Brunswick, Canada, for example, the leak of a local doctor's positive COVID-19 result led to

²² Bishop, T. (2020, May 17). COVID-19 lessons from Iceland: How one Nordic country has all but stopped the virus in its track. *GeekWire*. <u>https://perma.cc/RKS6-LG4G</u>

²³ Alexander, M. (2018). The 11 languages of South Africa. *South Africa Gateway*. Retrieved from <u>https://southafrica-info.com/arts-culture/11-languages-south-africa/</u>

²⁴ Digital Health & Care Scotland. (2020). Interim National Equality Impact Assessment Protect Scotland App. *Digital Health & Care Scotland*. Retrieved from <u>https://www.protect.scot/resources/docs/EQIA-17-september-2020.pdf</u>

him being labelled as "patient zero" of the local outbreak, the target of racist threats, rejected by his community, and a scapegoat for local officials.²⁵ To encourage a more inclusive, human-rights preserving approach to D-CT implementation, these incentives must be equally available to all subsets of the population. This recommendation once again can increase accessibility and inclusivity by promoting equity and equality while also building a sense of community. Furthermore, in considering how integrally tied the D-CT process is with the response infrastructure, if action is taken to ensure equitable access to the response infrastructure, not only does the efficacy of D-CT improve but the efficacy of the response infrastructure also improves. Finally, returning to the discussion of robust and secure mechanisms to protect personal data and identities, taking these steps may influence perceptions of data collection and management, particularly if supported through policies.

9.3.4. CHALLENGE 4: Perceptions of D-CT app effectiveness are poor

Despite efforts to push D-CT apps, a large portion of the population may not download D-CT apps simply because they feel these apps are ineffective. This belief may stem from the lack of research able to formally demonstrate the effectiveness of D-CT initiatives, the flood of negative media highlighting the digital capability issues (i.e. inaccuracies in Bluetooth proximity measurement, risk of false positives, challenges with incubation periods), and/or misinformation linked to the purpose of these apps. This lack of buy-in into the effectiveness of these apps may be sufficient to let perceived risks associated with these apps described above outweigh the benefits. These recommendations address the Digital Capability factor alongside a variety of other factors, as outlined in Table 9.4.0.

	MICRO	М	ESO	MACRO					
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8	
RECOMMENDATIONS	Perceptions of Data	Sense of Community	Communications & Misinformation	Accessibility & Inclusion	Trust in Government	Policy & Governance	Response Infrastructure	Digital Capability	
CHALLENGE 4: Perceptions of D-CT	app effective	ness are poo	r						
Build, Strengthen & Communicate the Relationship Between Manual and Digital Contact Tracing									
Strive to limit false positives; strive to better embed incubation and infection risk into D-CT software								~	
Minimize Digital Glitches									
Build Communication Channels Between App-Users and App Developers									
Build App Functionality									

Table 9.4.0: Challenge 4 Recommendations and Corresponding Factors Addressed

9.3.4.1. Build, Strengthen, & Communicate the Relationship Between Manual and Digital Contact Tracing

Building, strengthening, and communicating the relationship between manual and digital contact tracing can address six of the eight factors: 1) Communications & Misinformation; 2) Accessibility & Inclusion; 3) Trust in Government; 4) Policy & Governance; 5) Response Infrastructure; and 6) Digital Capability. Research identified that digital exposure notifications from D-CT apps may not provide the same sense of

²⁵ Levinson-King, R. (2020, Nov 25). New Brunswick outbreak: How a smalltown doctor became a Covid pariah. *BBC News*. Retrieved from <u>https://www.bbc.com/news/world-us-canada-54686672</u>

urgency as a phone call would be from a contact tracer. As a result, D-CT app users may not take the necessary next steps to isolate. This risk may be minimized by fully integrating the app into the M-CT system. For instance, at-risk individuals (if they enter their phone number voluntarily) can be contacted by a member of the contact tracing team in the case of an exposure. The success of the app in Iceland, for example, has been partially attributed to their approach to the app as a supplement to M-CT.²⁶ Linking contact tracing apps to public health infrastructure so individuals who receive exposure notifications are given further useful instructions through discussions with a contact tracer not only promotes the sharing of accurate information (and subsequent appropriate action), but also may improve perceptions of the usefulness of the app (digital capability of the app). Where the integration of M-CT and D-CT increases the efficacy of user response to COVID-19 exposure notifications, it may improve the perceptions of the response infrastructure's capacity as well as trust in the government's response to the pandemic. Relatedly, upon being involved in the M-CT process and experiencing the activities and outcomes of M-CT and D-CT integration, users may have a better understanding of how the contact tracing system works and how the government is using a user's data. These outcomes may ultimately improve trust towards the government and its response. Meanwhile, for communities that may not have digital access to D-CT apps, they are still included in manual methods of contact tracing, thereby increasing the inclusivity of the contact tracing process as an integrated process. Certainly, the integration of D-CT and M-CT should be fortified via policy to ensure privacy regulations are followed, to govern how data will be exchanged, and protect privacy rights alongside other human rights, such as the right to equality and freedom from discrimination.

9.3.4.2. Strive to limit false positives; strive to better embed incubation and infection risk into D-CT software

Improving the digital capability of D-CT apps by improving the software, addresses two of the eight factors: 1) Response Infrastructure; and 2) Digital Capability. Currently, most D-CT apps rely upon the standard measurement of 6 ft for 15 minutes as its base for registering a potential exposure. While it is currently inconclusive whether this measurement in itself is accurate, there also is the consideration that the COVID-19 virus may last on surfaces and therefore be transmitted should someone touch their eyes, nose, or mouth. Furthermore, it is important to note that Bluetooth-based D-CT apps cannot recognize walls, therefore if one person contracts COVID-19 and is isolating in one apartment, their neighbours may receive an exposure notification despite the neighbours having no true exposure to the COVID-19 positive individual. These factors suggest that the risk calculation is fairly ineffective at determining exposure risk and can ultimately result in false positives.²⁷ Therefore, it is important to continue developing D-CT software to limit false positives. In doing so, users may gain confidence in the efficacy of the D-CT app system as well as the emergency response infrastructure overall. This improved perception may mean that the individual is more likely to isolate which also assists in improving the efficacy of the COVID-19 response. Limiting the amount of false positives also can reduce the negative impacts that occur due to work and social disruption. Not only can work be done to limit false positives, but an individual's infection

²⁶ NPR Weekend Edition Sunday. (2020, May 17). How Iceland handles contact tracing [Audio recording]. <u>https://perma.cc/EBW8-</u> 2QQZ.

²⁷ Masel, J., (2020, October 28). *Risk Scoring in GAEN Applications* [Video file]. Retrieved from <u>https://www.youtube.com/watch?v=EG_Bd5Y2MvY</u>

risk and incubation period can be embedded into the D-CT software to determine an individual's necessary isolation time. This also can improve perceptions of the D-CT app's digital capability as well as the response infrastructure as a whole.²⁸

9.3.4.3. Minimize Digital Glitches

To optimize D-CT app benefits to users, implementers and developers must identify, assess, and correct technological glitches, especially those that force users to uninstall and reinstall the app (a process that causes the user's personal and geolocation data to be lost). This recommendation addresses four factors: 1) Communications & Misinformation; 2) Accessibility & Inclusion; 3) Response Infrastructure; and 4) Digital Capability. Across the case studies, there was public disappointment in the quality of their D-CT apps at various times. Many users in Cyprus for instance, claimed that the app did not work at all (see Module 3, Section 3.2.2.4).²⁹ Correcting such glitches can help build the effectiveness of these apps and ultimately, improve the response infrastructure. Furthermore, it may also positively influence the user's perceived effectiveness of these apps and response infrastructure. Relatedly, when glitches occur and users have a negative experience and express it through reviews or social media, it creates a negative narrative about the app. By reducing glitches or fixing them as quickly as possible, it is possible to mitigate the potential deleterious impact of such narratives. Furthermore, if government and developer communications with the public about glitches are transparent and timely, there also arises the opportunity for users' negative perceptions about the app to be altered because there is a solution on the horizon. Finally, there is a component of improving accessibility by removing digital barriers for users.

9.3.4.4. Build Communication Channels Between App Users and App Developers

Building communication channels between app users and app developers can potentially address five factors: 1) Perceptions of Data Collection & Management 2) Communications & Misinformation; 3) Accessibility & Inclusion; 4) Trust in Government; 5) Digital Capability. D-CT developers should consider increasing their presence across all social media platforms as this will allow users to communicate quickly and directly with the D-CT app team (as opposed to emails which are less efficient and timely). Currently, in Cyprus, three of the four social media links (Facebook, Twitter, and Instagram) of CovTracer's developer (RISE) redirect visitors to error pages. For a technology non-profit like RISE, this is problematic as it decreases real and perceived efficacy and authenticity if channels of communication are defective. In today's social media age, it is essential for D-CT apps to have an online presence to help build transparency around the app. Alternatively, much like Iceland's built-in chat feature to their Rakning C-19 app with responders, similar functionality could be built to chat with app developers to address questions and concerns related to efficacy to privacy. Building communication channels will not only promote transparent and timely communication, but it could lead to conversations and the sharing of information that change perceptions of data collection and management, the efficacy of the app, and trust towards public and private institutions. Furthermore, building these platforms can improve accessibility for users to share their concerns or app issues. Relatedly, if persons from marginalized, vulnerable, or excluded groups

²⁸ Ibid.

²⁹ Google Play. (n.d.). CovTracer - Apps on Google Play. Retrieved from <u>https://play.google.com/store/apps/details?id=edu.rise.ihnilatis&hl=en&gl=US</u>

are able to voice their desire to be included and/or considered in D-CT app development, there also arises the potential for developers to ultimately develop an app that is more inclusive.

9.3.4.5. Build App Functionality

Building app functionality may mitigate the risk and optimize the benefit for users of D-CT apps by addressing five of the eight factors: 1) Perceptions of Data Collection & Management; 2) Communications & Misinformation; 3) Accessibility & Inclusion; 4) Response Infrastructure; and 5) Digital Capability. Some cases studied integrated features beyond contact tracing into their apps (e.g. Iceland, Ireland, and Cyprus). For example, Iceland integrated a chat feature to enable users to connect with health officials. Although the impacts on uptake are inconclusive at this time, it is hypothesized that added functionality may encourage uptake, but may also facilitate the second stage of engagement (app use). Scotland's experience with women being harassed after providing their contact details in bars and other public establishments for manual contact tracing further suggests the benefit of increasing app functionality. For instance, users could sign into hospitality services and other locations through the *Protect Scotland* app, eliminating the need to physically leave personal information. This situation in particular highlights how additional functionality could improve inclusivity by incentivizing certain populations - such as women to download the app, or alternatively reduce risks associated with M-CT for other populations. Relatedly, the transition from physical to digital sharing of information may positively influence perceptions related to data collection and management by minimizing the risks associated with malicious actors who are exploiting physical data. Finally, by adding additional features to a D-CT app – whether it be chat features for health officials, additional information for tourists, or a symptom check-in feature - not only may users perceive the digital capability of the app to be improved, but broadly may influence users' perception of the capacity of the response infrastructure as many additional services or resources are available to users via their phone.

9.3.5. CHALLENGE 5: Digital limitations inhibit people from downloading D-CT apps

As with any digital intervention, there is always the risk that a proportion of the population will not be able to engage in full capacity or at all due to digital limitations. These limitations may include a lack of phone ownership, an out-of-date phone, or residing and/or working in an area with limited to no internet connectivity. The risk associated with the digital divide is particularly prevalent with this challenge, given that D-CT apps are specifically designed for smart phones with very specific technical requirements, connectivity needs, and digital literacy capacity. Given the effectiveness of these apps depends so heavily on widespread representation of the population, this population is at risk of not being alerted of exposure without access to these apps and the effectiveness of these apps are at risk when key sources of the virus may not be traceable (i.e. digitally connected). Furthermore, it is often the populations that are excluded from D-CT apps due to the digital divide that also are disproportionately impacted by COVID-19 and could have the most to gain from such an app. The following recommendations address the Accessibility & Inclusion factor while touching upon other factors, such as Digital Capability, as outlined in Table 9.5.0.

	5					1 5				
	MICRO	MESO		MACRO						
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5	Factor 6	Factor 7	Factor 8		
RECOMMENDATIONS	Perceptions of Data	Sense of Community	Communications & Misinformation	Accessibility & Inclusion	Trust in Government	Policy & Governance	Response Infrastructure	Digital Capability		
CHALLENGE 5: Digital limitations inhibit people from downloading D-CT apps										
Minimize Technical & Connectivity Requirements		\checkmark								
Make App-Installation and App-Use Tutorials That are Brief										
Supply Individuals with Mobile Phones or Alternative Technologies to enable Participation										

Table 9.5.0: Challenge 5 Recommendations and Corresponding Factors Addressed

9.3.5.1. Minimize Technical & Connectivity Requirements

Minimizing D-CT apps' technical and connectivity requirements can address three of the eight factors: 1) Sense of Community; and 2) Accessibility & Inclusion; 3) Digital Capability. To include individuals with older phones, poor-connectivity, and/or low-income, apps should be designed to be as inclusive as possible by reducing digital limitations. In South Africa, for example, the *COVID Alert SA* app has been designed to require little phone space (3MB) and the government has worked together with mobile phone companies to make the app zero-rated, i.e. people are not charged for the data required to download the app. Whereas this action improves inclusivity and accessibility, the operating system requirements of the D-CT apps studied span iOS 9.0 up to 13.5 and Android 5.0 to 6.0 which reduces accessibility because individuals with prior versions are unable to download the app. Lowering digital requirements also can contribute to building a sense of community because the app is designed to be inclusive of as many communities as possible and equally accessible. Beyond accessibility and inclusivity, expanding the types of phones and operating systems that the app can run on for instance, also improves the app's digital capabilities which can change people's perceptions of the app's efficacy, thereby influencing app-uptake.

9.3.5.2. Make App-Installation and App-Use Tutorials That are Brief

Brief app-installation and app-use tutorials can address three factors: 1) Communications & Misinformation; 2) Accessibility & Inclusion; and 3) Digital Capability. D-CT app implementers can take the lead from countries such as Canada, Ireland, and Israel and create a tutorial video that briefly describes the app and walks users through app installation, setting customization, app use, and data sharing. However, as most tutorial videos exceed two minutes and research indicates that the average human attention has dropped from twelve seconds to eight seconds,³⁰ this study's research team proposes TikTok-style videos that guide users through app installation, use, and sharing in 60 seconds or less. Tutorial videos can address individuals' unfamiliarity or misconceptions surrounding data collection and management and strengthen transparency and share accurate information. Furthermore, by including videos in different languages – such as sign language – the app can be made inclusive of more populations. Finally, these tutorials can address digital literacy issues which will help mitigate negative perceptions of the app's digital capability.

³⁰ Desk, W. (2018, September 10). The Human Attention Span [INFOGRAPHIC]. *Digital Information World*. Retrieved from <u>https://www.digitalinformationworld.com/2018/09/the-human-attention-span-infographic.html</u>

9.3.5.3. Supply Individuals with Mobile Phones or Alternative Technologies to enable Participation

Supplying phones or alternative technologies to individuals can assist in addressing four factors: 1) Sense of Community; 2) Accessibility & Inclusion; 3) Response Infrastructure; and 4) Digital Capability. As highlighted in Module 1, other countries have started to use other forms of digital technologies such as QR codes (that do not require download of an app) and eBracelets or wearable tokens (which work on Bluetooth but do not require a mobile phone). Some are offered for free, as seen in Singapore.³¹ The above efforts are aiming to engage populations that may otherwise be disconnected. The potential effect of increasing accessibility and inclusivity can be improving a sense of community. Furthermore, increasing the individuals with the digital capacity to engage with D-CT can increase the capacity of the response infrastructure to connect with those that may have been previously disconnected. Finally, when individuals are supplied with a mobile phone that can download the app or provided with alternative technologies designed to interface with the D-CT app, it therefore expands the digital capability of D-CT apps to have an impact.

9.4. Future Research

Our research alongside the broader literature has highlighted gaps or areas that need further exploration to understand user engagement with D-CT apps in relation to efficacy. Some of these areas align with research we have reported but also gaps we have been unable to report on given insufficient data or longevity of D-CT apps in use. These fall under three main categories. The first area of study is regarding the user-uptake phase of user engagement specifically. Our research was a preliminary exploration of the factors potentially impacting user-uptake within the broader user engagement framework but further understanding, such as how to most appropriately measure user-uptake, is required. The second area of study is the other three phases of research: use, report, react. While this project briefly described the user engagement process within the case studies, in-depth research is required to fully explore the factors that impact each stage of user engagement as well as what success looks like within each stage and across the stages. The final area of study is in relation to this research topic in general. For instance, exploring different regions, increasing the granularity of the study's focus, and the effectiveness of D-CT apps in general are all future avenues of research.

9.4.1. Uptake Phase of User Engagement

This section outlines four potential avenues of research that relate specifically to the uptake phase of user engagement. This includes, first, **examining the factors identified in this project in further depth**. For example, following our findings regarding misinformation and community-focused messaging, more understanding is needed on how narratives develop around the app and the impact of these narratives on the uptake and usage of these D-CT apps. By investigating these narratives, governments and creators will be able to better reach their intended audience and will provide an understanding as to why and how users react to these perceptions of these apps. Second, relatedly, there is the need for **quantitative study**

³¹ BBC News. (2020, September 14). Singapore distributes Covid contact-tracing tokens. *BBC News*. Retrieved from <u>https://www.bbc.com/news/business-54143015</u>

of the factors identified in this research, specifically to evaluate if they have a quantifiable impact on uptake, the nature of their impact, and how they may correlate with other factors. Although our study was able to identify recurrent themes that appear to influence uptake, without quantitative study it is difficult to truly understand the nature of their influence. Third, **the study of uptake curves i.e. graphs of how uptake rates vary over time** is needed, specifically looking at moments of change in these curves as potential inflection points for research. This may include, for example, looking at where and why uptake may decrease after initial release (which was often observed in our study). Investigating drops in the uptake curve after a certain amount of time or due to an additional factor, such as technological issues, will help identify where and what counter measures need to be taken to continue the amount of useruptake of the apps, enabling higher uptake and usage.

Finally, future research **must find better ways to measure uptake**. In many cases, D-CT app download numbers are unknown, outdated, estimated, or inaccurate. This is, in part, due to data limitations. In the case studies it was extremely challenging to determine uptake amongst the population that own phones that can download the app (referred to as digital capability uptake) versus those that lack this capability, or those that are within eligible age limits. Relatedly, our research found that uptake measurement in terms of registrations are more accurate, yet only one country (Ireland) could find metrics beyond aggregate downloads. Looking into what these numbers are and why they are hard to find as well as studying which demographics are downloading the app and how they interact with the app may aid in researching ways to better characterize uptake and understand how uptake is affected over time across contexts.

9.4.2. Other Stages of User Engagement (use, report, react)

Beyond user-uptake (the first phase of user engagement), there is a need to study the other stages of user engagement - use, report, and react (see the four-stage continuum of D-CT engagement in Module 1, Section 1.5) through a risk-benefit lens. Specifically, while the media tends to focus on uptake rates as a measure of success for D-CT apps, app effectiveness also requires users to engage in the other three phases. Therefore, understanding what success looks like individually within each of the phases as well as collectively is an important area of study as it may help explain the disconnect between an app's number of downloads and the number of positive COVID-19 diagnoses reported via the app (a recurrent theme in the research). Relatedly, how success is defined may vary between contexts suggesting a further research area. It is uncertain if success should be measured through the number of downloads of the app, whether this metric involves redownloads, the number of users who consent to share data, and/or the number of actual app users as well as other unidentified factors which may contribute to uptake numbers and measures of success. In Cyprus for example, a recent article reported that "21 out of 41 [COVID-19] cases were detected from the contact tracing process"; however, it is unclear if contact tracing meant manual contact tracing or D-CT through CovTracer. In simple terms what exact metrics are used by governments to determine uptake and thereby success and which metrics are not used (nor defined). Third, relatedly, the types of incentives and their relationship with success is a worthy area to study. This research would help further understanding of why some users engage and others do not, as well how to reach users that are either disinterested or inaccessible. For instance, incentives may be useful in bridging the gap between app users who have tested positive and forget to

input their code given by public health into contact tracing apps.³² Beyond factors identified, it was difficult to identify specific incentives that encouraged users to download D-CT for example. Meanwhile, initial focus group research suggested that incentives from financial reward to access to treatment can be important conduits to bridge engagement. Finally, **recognizing which populations are excluded or have particularly low uptake and why** can help in finding ways to reach out to these populations further expanding uptake and usage. As seen in a 2018 report from Scotland, certain populations such as minority groups, people with disabilities, and seniors are more likely to be digitally excluded.³³

9.4.3. General Areas of Study

There also are gaps within this general area of study that require further research. First, the scale of study can be varied. For instance, this study focused on various countries, but more insight could be gained by focusing on specific regions and facilitating cross-country comparisons. Alternatively, increasing the granularity and comparing cities like Madrid versus Lisbon could be extremely insightful. There may be some benefit in narrowing the focus of research and analysing regions and cities that may have higher infection rates than the general population or that may have slowed the spread more effectively then the surrounding regions. Second, relatedly, there is a **need to study more of the global south**. Given the experience many countries in Africa have with epidemics, for example, some countries in Africa have fared better than many in the global north during the COVID-19 pandemic. Understanding why they have done so would be useful for future disaster and emergency response measures. Third, evaluating the dynamics between manual and digital contact tracing could lead to identifying ways to generate optimal impact, and improve the broader the efficacy of the contribution of D-CT to disaster and emergency response. Fourth, due to the relative novelty of D-CT apps, it is important to continue to measure the effectiveness of these D-CT interventions through reflective study on the apps implemented thus far, taking into account other D-CT interventions³⁴ (e.g. QR codes, eBracelets and tokens described in Module 1) and their relationship to one another. Relatedly, the final area of study is exploring, understanding, and evolving the technology behind these apps to further build digital capability. For instance, examining Bluetooth functionality and efficacy is frequently questioned as research has found that "Bluetooth attenuation is not a reliable measure of distance." ³⁵ Despite guidelines such as the WHO standard risk measurements, constantly advancing science dictates the need for more accurate and precise methods of measurement. There must be continued research into technological specifics such as Bluetooth functionality, the underlying risk calculations, secure data management, and accessible development. Ensuring that these apps function in a way that rewards the time and resources

³² O'Sullivan, K. (2020). Protect Scotland app has notified more than 10,000 contacts of positive cases, First Minister confirms. *FutureScot*. Retrieved from <u>https://futurescot.com/protect-scotland-app-has-notified-more-than-10000-contacts-of-positive-cases-first-minister-confirms/</u>

³³ Sawers, L. (2018). Is Scotland Fairer? The state of equality and human rights 2018. *Equality and Human Rights Commission*. Retrieved from <u>https://www.equalityhumanrights.com/en/publication-download/scotland-fairer-2018</u>

³⁴ Goldstein, D., Babcock, R., (2020, Nov 12). More Than Just An App: the Many Forms of D-CT During COVID-19. *Digital Global Health & Humanitarianism Lab*. Retreived from <u>https://dghhlab.com/more-than-just-an-app-the-many-forms-of-d-ct-during-covid-19/</u>

³⁵ Wilson, A. M., Aviles, N., Beamer, P. I., Szabo, Z., Ernst, K. C., & Masel, J. (2020). Quantifying SARS-CoV-2 infection risk within the Apple/Google exposure notification framework to inform quarantine recommendations. *MedRxiv*. <u>https://doi.org/10.1101/2020.07.17.20156539</u>

committed to them, as well as are usable by all audiences regardless of disability are all topics without which app development may stagnate.

9.5. Conclusion

Module 9 provided an overview of the recommendations and future research identified as a result of our research. The recommendations were organized based on the challenge they address. Five challenges – 1) fears of immediate and future surveillance, and alternative uses of personal data; 2) privacy perceptions may override privacy-by-design principles; 3) some communities are disproportionately affected by and/or excluded from D-CT apps/measures; 4) Perceptions of D-CT app effectiveness are poor; and 5) digital limitations inhibit people from downloading D-CT apps – were identified. Numerous recommendations were provided for each challenge and also provided insight into which of the eight individual (micro), community (meso), and system (macro) level factors were addressed by each recommendation. Future research areas were grouped into three main categories: 1) uptake phase of user engagement; 2) other stages of user engagement (use, report, react); and 3) general areas of study. A number of potential research avenues were posed for each category. For an overview of the individual (micro), community (meso), and community-system (meso-macro) level factors influencing user-uptake, see Module 7. For an overview of the system (macro) level factors influence user-uptake, see Module 8. Alternatively, for the case studies, see Modules 2-6.