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Key Considerations for Advancing the Development and Testing of mHealth Interventions in Adolescent and Young Adult Oncology

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Mobile health (mHealth) interventions have the capacity to help enhance care for adolescent and young adult (AYA) cancer survivors throughout the care continuum by transmitting data and resources in real-time between patients and the healthcare team across geographic boundaries. In AYA oncology, access to resources varies by survivor characteristics, healthcare system, and geographic location. AYA cancer survivors can use mHealth applications to assist with symptom management and healthcare surveillance. The scientific research on mHealth interventions in AYA oncology is in the early stages of usability and feasibility testing.

Time and resource constraints create barriers to developing and testing mHealth interventions with AYA cancer survivors. The purpose of this commentary is to review strategies we have identified that could help to advance mHealth intervention research in AYA oncology. Drawing upon mHealth intervention development and research evaluation tools [1–4] and newly released World Health Organization digital health intervention guidelines [5], we highlight five research considerations and their relevance in AYA oncology: 1) User feedback and involvement, 2) Interoperability, 3) Cost assessments and sustainability, 4) Data security, and 5) Standardized reporting tools.

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1) User feedback and involvement.

AYAs (defined as those diagnosed with cancer between the ages of 15–39) face unique psychosocial, developmental, and medical challenges, such as social isolation, fertility preservation, and disruptions in work/school. These challenges translate to specific, and often unmet, medical and psychosocial needs [6]. User feedback and involvement should be prioritized at the onset, and include feedback about design, features, and content.

Usability testing is an iterative process of testing the intervention's user-interface with the intended population and applying the findings to customize the app to meet the user needs. A step-by-step usability testing guide is available for free electronic download (www.usability.gov) [7]. As an example in AYA oncology, researchers who developed the Pain Squad+ real-time pain self-management app for adolescents with cancer conducted three iterative usability testing cycles involving observation of adolescents using the app while “thinking aloud” about issues encountered followed by semi-structured interviews about the experience [8]. Usability testing informs the efficiency, ease of use, and acceptability of mHealth applications.

2) Interoperability.

Interoperability is the integration of mHealth interventions into existing health information systems [1]. AYA cancer patients want to engage in real-time with their health data and healthcare providers. AYA cancer care in the United States is delivered across a broad range of healthcare settings, including pediatric, adult, academic, and community-based centers. Interoperability is needed to determine how mHealth interventions may impact current workflows and improve existing processes [1]. Newly released guidelines from the World Health Organization emphasize that mHealth interventions should complement existing models of care through mechanisms such as accelerated exchange of information, but will not replace the key components needed by health systems, such as the health workforce [5].

mHealth apps are usually developed as independent systems in which the patient's information is either stored on personal mobile devices or on web platforms but is not integrated with the patient's health record [9]. The transfer of information from mHealth apps to electronic health record (EHR) systems is rare [9]. A 10-year national plan for the advancement of connectivity and interoperability of health information technology has been released, “Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap version 1.0” [4]. Ongoing national efforts towards interoperability will enhance the capabilities of AYA oncology programs to integrate mHealth interventions into their existing health information systems.

3) Cost Assessments and Sustainability.

Published manuscripts of mHealth interventions in AYA oncology do not consistently include the associated costs of software and information technology services. Situational factors, such as institutional support and grant funding, can change throughout the mHealth intervention development and implementation cycle. Resource constraints can impact the scalability of mHealth intervention research in AYA oncology. To determine the financial

resources needed for an mHealth intervention to be accessible and sustainable in AYA oncology, detailed cost assessments can be conducted at each stage of app development and testing.

One tool that may be used is a standardized economic evaluation checklist, such as the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement [2]. A few of the checklist items include the target population and sub-groups, setting and location, choice of health outcomes, comparators, and the time over which costs and consequences were evaluated. In AYA oncology, examples of strategies suggested to reduce costs include using older models of phones that may be available for low-cost or free and designing apps that are device and platform agnostic. Cost-savings opportunities for institutions are also helpful to track and report, such as direct data entry from mobile devices potentially eliminating the costs of data entry and validation by staff.

4) Data security.

The collection, storage, and exchange of sensitive health information using mobile phones raises complex data security concerns, such as breach of data and data sharing. Data security procedures must be taken at the time of data collection, as well as during the transmission, storage and access of information [1]. Conducting an information security risk assessment supports compliance with the Health Insurance Portability and Accountability Act (HIPAA) Security Rule to ensure the confidentiality, integrity, and security of electronic protected health information [3]. The Office of the National Coordinator for Health Information Technology, in collaboration with the Health and Human Services Office for Civil Rights, has developed a downloadable security risk assessment tool [3]. If available at a researcher's home institution, there may be opportunities to collaborate with the information security department.

Although AYAs are active users on social media, they are often as or more concerned than older adults about determining who sees their cancer history and health concerns. Consequently security of their health information on an app needs to be both assured and communicated to AYAs. Data security procedures, such as those described in the testing of an electronic diary for AYAs with cancer to record symptoms [10], include data being delivered to a secure website, listed by study number only. Alternatively, if the data is stored exclusively on the mobile device itself, this restricts access to those with the phone in hand.

5) Standardized reporting tools.

Variability in AYA age group definitions and in the reporting of mHealth interventions creates challenges with aggregating data, identifying opportunities for improvement, and replicating interventions. The use of standardized checklists helps to foster consistency in presenting and publishing across studies. The mHealth evidence reporting and assessment (mERA) checklist is a standardized reporting tool used to define the content, context, and technical features of the mHealth intervention [1]. When reporting studies of apps for cancer survivors, we recommend noting results for those in the AYA age range distinctly so that adaptations can be made accordingly.

AYAs preferences for technology-based resources will continue to drive the development and use of mHealth interventions in AYA cancer care. These five considerations and related resources (Appendix; Table 1) are intended to help advance mHealth intervention research in AYA oncology. All aspects of mHealth intervention research in AYA oncology require ongoing monitoring and cross-disciplinary discussion as new opportunities, threats, and resources arise in the changing mHealth technology landscape.

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Appendix

Table 1.

Resources for mHealth Intervention Research

Stage of mHealth Intervention Development	Key Points	Recommended Resource	Description of Resource	Electronic Resource Links
Usability Testing	User feedback and involvement should be prioritized at the onset, and include feedback about design, features, and content	Usability website [U.S. Department of Health and Human Services]	Provides detailed tutorials on all aspects of usability testing; training materials available for free electronic download	www.usability.gov
Cost Assessment	Cost and other resource assessment improves the likelihood of an app being sustainable in practice for both AYAs and providers	Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement [Husereau et al., 2013]	User friendly, 24 item checklist for conducting health economic evaluations; available for free download	https://www.ispor.org/heor-resources/good-practices-for-outcomes-research/article/consolidated-health-economic-evaluation-reporting-standards-(cheers)----explanation-and-elaboration
Data Security	Data security procedures must be taken at the time of data collection, as well as during the transmission, storage, and accessing of information	Security Risk Assessment Tool [Office of the National Coordinator for Health Information Technology & the HHS Office for Civil Rights]	Used to assess risks of the confidentiality, integrity, and availability of electronic protected health information; available for free download	https://www.healthit.gov/topic/privacy-security-and-hipaa/security-risk-assessment-tool
Standardized Reporting	Helps to foster consistency in presenting and publishing across studies	mHealth evidence reporting and assessment (mERA) checklist [World Health Organization mHealth Technical Evidence Review Group]	16 item checklist for providing the minimum amount of information needed to define the content, context, and technical features of the mHealth intervention; available for free download	https://www.bmj.com/content/352/bmj.i1174.long

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Key Points:

1. Scientific research on mHealth interventions in Adolescent and Young Adult (AYA) oncology is in the early stages of usability and feasibility testing, with a focus on symptom management and healthcare surveillance.
2. Detailed cost assessments of mobile app development and testing can be conducted using the Consolidated Health Economic Evaluation Reporting Standards (CHEERS) statement.
3. Data security procedures must be taken at the time of data collection, as well as during the transmission, storage and accessing of information.
4. Use of the mHealth evidence reporting and assessment (mERA) checklist can help to foster consistency in presenting and publishing across mHealth intervention studies.
5. AYAs' preferences for technology-based resources will continue to drive the development and use of mHealth interventions in AYA cancer care.