

Supplementary File 1.

Study Implementation Materials

Purpose: This supplementary file contains procedural materials developed to standardize telemedicine platform implementation across the research team. It provides step-by-step guidance for research staff involved in participant recruitment, consent procedures, platform onboarding, and consultation management.

Contents

- Pre-study preparation and participant recruitment
- Phase 1: Research consent procedures and staff training
- Phase 2: Post-consent and survey administration
- Phase 3: Day before telemedicine consultation
- Phase 4: During telemedicine consultation
- Phase 5: Post-consultation procedures
- Phase 6: Final participant survey

Pre-study preparation	1. Prepare follow-up available data by physician 2. Set up SurveyMonkey survey links 3. Prepare sufficient copies of questionnaires, consent form 1 (pediatric version), consent form 2 (guardian version), and business cards
Participant Recruitment	1. Attending physician assessment: Identify patients eligible for telemedicine follow-up over approximately 18 months 2. Observe clinic visit and randomly assign to experimental or control group Physicians select eligible patients and provide brief introduction to telemedicine 3. Research staff: Among patients informed by the physician, proceed with appropriate guidance by group assignment - Control group: Administer questionnaire only - Experimental group: Recommend telemedicine, schedule next telemedicine appointment, explain care diary documentation, and review patient responsibilities 4. Research team: Record patient name and registration number, assign study ID number
Phase 1. Consent and staff training	1. Obtain research consent • Age-appropriate patient consent form • Guardian/caregiver consent form 2. Administer surveys at the hospital whenever possible — paper questionnaires (A, B, C, D, E) • Surveys to be completed on-site: B, D • Surveys to be completed at home: A, C, E (via SurveyMonkey) • Distribute educational materials with embedded QR codes • Share survey links via the 'Rare Disease Research' channel • Record which participants will complete surveys after returning home 3. Access hospital admin system (tablet/laptop) • Register patient: patient name, registration number (+ diagnosis)

	- On the patient's mobile phone: access KakaoTalk and add '올라케어 희귀질환 자기관리 (OllaCare Rare Disease Self-Management)' channel and '희귀질환연구 (Rare Disease Research)' channel - OllaCare Rare Disease Self-Management channel → Sign up → Schedule appointment - Step 1: Sign up / registration - Step 2: [Patient role] → Add family member → Enter child's information and complete family registration - Step 3: [Symptom description] - If disease list is not updated: select 'Other' under [Disease Selection], enter diagnosis name in symptom description → Enter current symptoms → Enter patient, guardian, and caregiver contact information - Step 4: [DO NOT use the appointment booking button] — Strictly educate that appointment booking must NOT be used - Access hospital admin system again - Reception → Waiting for consultation → Consultation complete → Enter consultation information (follow-up date, patient tasks) → Confirm in waiting queue - Provide and explain the telemedicine information sheet (distribute with business card) - Demonstrate care diary entry shown in item '2' of the information sheet (educational material uploaded to 'Rare Disease Research' channel) - Educate on medical fee payment and prescription pickup procedures Inform participants that mid-study feedback will be collected (electronic consent forms and feedback surveys will be distributed)
Phase 2 Post-Consent and Survey Administration	- Check EMR and enter patient appointment date and patient tasks in hospital admin system - Follow up with participants who planned to complete surveys at home to confirm completion - Organize survey responses in Excel - Send coffee vouchers to survey respondents
Phase 3. Day before Telemedicine Consultation	- Notify patients and guardians of pre-consultation questionnaires and items to prepare for telemedicine visit - Summarize care diary entries - Send patient announcements/reminders
Phase 4. During Telemedicine Consultation	- Prepare laptop with three screens open simultaneously: physician's EMR, hospital admin system, and video consultation solution - Confirm physician's available follow-up dates - Ensure all 'patient tasks' are checked without omission
Phase 5. Post-consultation Procedures	- Update follow-up date and patient tasks in hospital admin system - Administer post-consultation satisfaction survey - Confirm post-consultation document, prescription, and payment processes - Update patient consultation flow / telemedicine schedule in shared outpatient sheet
Phase 6. Final Participant Survey	Administer final survey approximately 1 year after enrollment